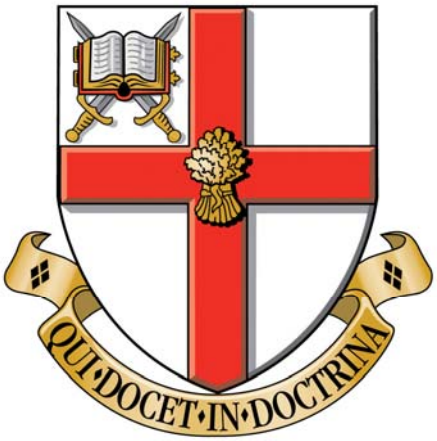

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Anxiety and Depression Symptomatology in Adult Siblings of Disabled Individuals: The role of Perceived Parenting, Attachment, Personality Traits and Disability Types

Thesis submitted in accordance with the requirements of the University of Liverpool for the degree of Doctor of Philosophy by Linda Patricia O'Neill

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ABBREVIATIONS

ASD	Autistic Spectrum Disorder
CCS	Cybernetic Coping Scale
CES-D	Center for Epidemiological Studies Depression Scale
DPCS	Descriptions of Parental Caregiving Scale
DS	Down's syndrome
ECR	Experiences in Close Relationships
GHQ	General Health Questionnaire
HADS	Hospital Anxiety and Depression Scale
IPIP	International Personality Item Pool
LCS	Locus of Control Scale
MSPSS	Multidimensional Scale of Perceived Social Support
PWS	Prader-Willi syndrome
RSES	Rosenberg Self Esteem Scale
SDI	Sibling of a Disabled Individual

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This thesis is dedicated to the memory of my father, James Reid,

1.11.1932 – 15.12.2012

ABSTRACT

Objectives: (1) To ascertain whether adult siblings of disabled individuals are more prone to anxiety and depression symptomatology than a closely matched control group. (2) To examine the contribution that perceived parenting styles, attachment styles and personality traits play in the long-term affective outcome of these siblings. (3) To consider if the type of disability has a role in sibling affective outcome.

Design: A cross-sectional, closely matched study design, with data collected through self-report. One-way ANOVAs, correlational analyses, moderation and mediation analyses were applied.

Participants: Adult siblings of disabled individuals (SDI), were initially contacted through support groups, such as SIBS, the Down's Syndrome Association, the National Autistic Society and the Prader-Willi Association (UK) and responded to a postal or e-mailed questionnaire; 150 participants returned the completed questionnaire. The 150 control group participants were closely matched on the variables of gender, age, marital status and when possible socio-economic status, in order to compare like with like. This group was contacted through friends, family, work colleagues and local businesses.

Measures: All the participants completed a range of demographic questions; the SDI were additionally asked questions regarding their disabled sibling. The established measures used included the Hospital and Anxiety Depression Scale (Zigmond & Snaith, 1983), Experiences in Close Relationships (Brennan, Clark & Shaver, 1998), an adapted measure of the Descriptions of Parental Caregiving Style (DPCS, Hazan & Shaver, 1986) and the International Personality Item Pool (Goldberg, 1999).

Results: The majority of SDI reported no increased anxiety or depression symptomatology, however, when compared the SDI did report higher levels of anxiety and depression symptomatology than the control group; also higher levels of perceived inconsistent mothering, attachment-related anxiety and neuroticism, with lower levels of extraversion than the control group. These variables mediated the path between having a disabled sibling and anxiety and depression, with the notable exception of perceived inconsistent mothering. This variable showed no association with any of the established measures for the SDI group; however, there were associations consistent with previous research for the control group.

There was no moderation effect on anxiety or depression between the demographic variables and SDI. The autistic spectrum disorder siblings reported similar levels of anxiety symptomatology to Prader-Willi siblings but higher than Down's syndrome siblings and the control group and they also reported the highest levels of depression symptomatology.

Conclusions: The adult SDI's higher propensity towards anxiety and depression is a cause for concern; particularly when explained through heightened levels of attachment-related anxiety, high levels of neuroticism and low levels of extraversion. The lack of association with perceived inconsistent mothering requires further investigation. These results can help guide interventions or clinical therapies; the emotional well-being of SDI is paramount as they will possibly be among the first group to assume responsibility for their disabled siblings.

Chapter 1

Literature Review

1.1 Introduction

This study examined the long-term impact of disabled individuals on their adult siblings. Due to the increase in medical technologies, many people with disabilities are now living to a much greater age. The responsibility for their long-term welfare often falls to their siblings when the parents are no longer able to cope with the demands that are placed upon them (Davys, Mitchell & Haigh, 2011). It is therefore necessary to ensure that the siblings are psychologically capable of carrying out this role. There has been much anecdotal evidence in self-support books and internet sites available to families with disabled children (e.g., Richardson, 2008) that having a brother or sister with disabilities increases the likelihood of the sibling without disabilities to experience emotional difficulties and that these difficulties can be persistent. This thesis consequently tried to empirically establish whether adults who have grown up alongside a disabled brother or sister reported more anxiety and /or depression symptomatology than a closely matched control group. The aetiology of any affective outcomes reported by the siblings was then examined through attachment styles, personality traits and different disability types.

Some research has indicated that having a disabled sibling as a child has little or no effect on the growing sibling without disabilities (Eisenberg, Baker & Blacher 1998; Midlarsky, Hannah, Shvil & Johnson, 2008); however, the majority of the evidence suggests a heightened potential susceptibility for siblings of disabled individuals to report increased anxiety and depression symptomatology (Gold, 1993; Moore, Howard & McLaughlin, 2002; Rossiter & Sharpe, 2001). As a result of the increased reporting of internalising disorders as children, further research into the impact of disability on adult siblings was recommended (Seltzer, Greenberg, Orsmond & Lounds, 2005). The aim of the thesis was, therefore, to try to establish if there is any difference in the long-term affective outcome as this can inform policy makers and highlight areas of potential concern for clinical practitioners and teachers in various disability disciplines, such as nursing, social work and occupational therapists.

This Chapter will examine the previous research that has been carried out on siblings of disabled individuals (henceforth to be referred to as SDI). The majority of research to date is on siblings as children but all available adult sibling research will be reviewed as well.

1.2 Siblings

1.2.1 Sibling relationships

Sibling relationships can offer one of the most mutually supportive and enduring bonds over the course of a lifetime (Bank & Kahn, 1997). If strong bonds are formed in the early years the sibling can offer continued help and advice throughout life, which can be a source of valued support (Voorpostel & Blieszner, 2008). It is not a relationship that is chosen but rather it is there through circumstance and because of shared influences it often tends to be a relationship of relative equals (Cicerreli, 1995). Sibling bonds can also create a wider learning process in both pleasurable and difficult situations (Howe & Recchia, 2006) and this can allow for development of understanding and accepting the viewpoints of others, which could improve emotional, cognitive and social growth (Brody, 2004).

The sibling influence can occur both directly and indirectly; directly when an older sibling assumes a teaching role for the younger sibling. This can have a bi-directional beneficial effect for both siblings, allowing the older sibling to develop in competence, self-esteem, to balance their needs with those of others and to gain an understanding of other people's perspectives. Likewise, the younger sibling gains confidence, ability and is able to appreciate others, due to the nurturance from the older sibling. Further, older siblings will often protect younger siblings during periods of parental conflict and consequently research has demonstrated that younger siblings who have experienced this show fewer signs of behavioural or emotional problems (Brody, 2004; Howe & Recchia, 2006). Indirectly, they can achieve vicarious pleasure from their older sibling's achievements, which can encourage them to seek achievement on their own merit. This could lead to improved self-esteem and a lessening of behavioural problems and depression symptoms, especially in younger siblings (Brody, 2004). Noller (2005) reported that siblings with high individual emotional adjustment reporting high quality sibling relationships achieve warmer, longer and more fulfilling sibling relationships than those who report lower quality relationships. Sibling warmth may offer a protective effect against trait anxiety for male and female siblings and against depression for males (Noller, 2005).

Research has shown that impressions of perceived parental differential treatment could lead to increased behavioural problems and depression symptom reporting. However, the perception of perceived differential parenting might be due to personality characteristics of the sibling, or due to parents treating the siblings as their individual personality characteristics require (Brody, 2004). Non-shared environment, including variables such as age, gender, birth order and the health of the individual might also account for parental differential treatment, with factors such as girls being expected to be more involved in household chores having a strong influence that could be instrumental in rivalry between siblings (Noller, 2005).

Perceived differential parenting can be influential in the development of attachment style; a twin study, using the Attachment Style Questionnaire (Feeney, Noller & Hanrahan, 1994) found that siblings who reported receiving less maternal affection than their twin were more likely to report less confidence in self and others and also high levels of anxiety, whereas those who perceived less paternal affection were more likely to report more discomfort with closeness to others (Sheehan & Noller, 2002). Perceived differential parenting could also have a negative impact on the sibling relationship, with the disfavoured sibling being more likely to use threats, insults and sarcasm towards their sibling (Noller, 2005). However, other research has suggested that the younger sibling may turn to the older sibling to provide attachment security in times of distress and parental unavailability (Gass, Jenkins & Dunn, 2007).

1.2.2 Sibling relationships when disability of a sibling occurs

When sibling disability occurs in a family there will inevitably be some restructuring of family roles to compensate for the additional time and resources required to look after the disabled child. Whilst some research indicates that in childhood some non-disabled siblings from these families appear psychologically well-adjusted (Carpenter, 2000; Cuskelly & Gunn, 2006; Pilowsky, Yirmiya, Doppelt, Gross-Tsur & Shalev, 2004; Stoneman, 2001), other research indicated fewer positive developmental outcomes (Banks et al. 2001; McHale & Gamble, 1989; Ross & Cuskelly, 2006). When one of the siblings has a disability; the status quo might be altered in terms of the SDI's responsibilities towards the disabled sibling, which might lead them to perceive the sibling bond as a caring function as opposed to being reciprocally supportive (McHale & Gamble, 1989; Turnbull & Turnbull, 1990). While

children with disabled siblings might benefit from these extra responsibilities (Midlarsky et al. 2008), a meta-analysis found that they could be at increased risk of developing affective disorders such as anxiety and depression (Rossiter & Sharpe, 2001). The majority of the research to date has focused upon the siblings as children but the long-term effects have still to be established. However, a recent review of the literature concerning adult SDI identified six themes that influenced sibling life with regards to the disability, these included life choices, relationships, identity and future plans (Davys et al. 2011). Many factors, however, impacted upon these themes and they included gender, current positions and potential future responsibilities, level of disability and health of both the disabled and non-disabled sibling. The multifarious responses to disability enforce the notion of individual differences in reaction to their siblings' situation, which should be taken into account if interventions or therapies are required. As only 23 articles on adult sibling to disability were found on the various databases, dating from 1977, it does suggest the necessity of much further research into this area.

1.2.3 Stressful life events and outcomes

The majority of children who experience stressful life events do not go on to develop any form of psychopathology (Gass et al. 2007); however, previous research has suggested that high levels of adversity in childhood significantly increase the lifelong propensity towards affective clinical conditions (Rosenman & Rodgers, 2006). These adverse events often include high levels of household conflict, nervous or depressed parenting styles and mental cruelty. This could lead to children developing high levels of the personality trait of neuroticism, behavioural inhibition and negative affect, and is particularly reflected in susceptibility towards avoidance and anxiety. These reactions displayed little difference between the genders or the age of the participant and it was proposed that the consequences related to these events, particularly negative affect and anxiety, could last throughout the lifespan (Rosenman & Rodgers, 2006).

Rossiter and Sharpe's (2001) meta-analysis on siblings of children with disabilities indicates that an issue affecting one member of a family could have an impact on all the other members; however, negative effects can be ameliorated through other siblings without disabilities, extra familial support, peer support, socio-economic status and level of education. The authors recommended that the severity of the disability should be included

when determining the extent of the impact on siblings. Their overall conclusion was that a number of SDI had elevated levels of affective symptoms, particularly depression (Rossiter & Sharpe, 2001). Similarly, another meta-analysis indicates that many of the same variables are influential in the affective outcome of the SDI but also suggests that it is the dynamic interaction between these factors that leads to numerous different familial responses to having a sibling with disabilities (Moore et al. 2002). Other research also suggests that the overall functioning of the SDI could be due to many factors. For example, better psychological adjustment occurs when educational levels between the SDI and disabled sibling are similar and when the SDI use problem-focused coping strategies (Orsmond & Seltzer, 2007). However, despite using different strategies or coping mechanisms, another study found that the SDI when children were more at risk of developing affective behavioural disorders than a comparison group (Ross & Cuskelly, 2007).

Children with disabled siblings also report more adjustment difficulties, emotional difficulties, peer problems and lower ratings of pro-social behaviour compared to a normative sample and are more prone to adjustment disorders (Giallo & Gavidia-Payne, 2006). Families at the lower end of the socio-economic scale are more likely to be at increased risk of adjustment problems but this risk could be ameliorated by lower levels of parental stress and family dynamics, such as good familial communication, family routines and time spent productively as a family (Giallo & Gavidia-Payne, 2006). Factors such as lowered socio-economic status, being male, only having the disabled child as a sibling and being older than the disabled sibling increased the risk of affective disorder in siblings of autistic children (Macks & Reeve, 2007); however, these authors also proposed that these siblings could have the advantage of increased emotional and social development if these demographic factors were not present. Further research has, however, shown that children with intellectual disabilities, and consequently their siblings, were more often born into socio-economically disadvantaged families (Olsson & Hwang, 2008). However, similarly to Macks and Reeves, Olsson and Hwang suggest that positive aspects of family dynamics, including parental health and lack of economic hardship, could have a protective effect on SDI well-being.

Parental education and family income have been positively associated with time for the SDI to pursue their own activities (Stoneman, Brody, Davis & Crapps, 1988); suggesting that a higher socio-economic background might provide protection against the SDI developing affective disorders due to being given more space to develop their own interests outside the immediate family, as opposed to helping to care for their disabled sibling.

However, multiple studies have indicated that SDI from middle-class families felt the need to excel in achievement in order to compensate for the lack of achievement from the disabled sibling (Moore et al. 2002; Powell & Gallagher, 1993); which could be viewed as potentially stressful for the child. Further, SDI from higher socio-economic classes may report higher perceptions of social stigmatization; while those SDI from the lower socio-economic classes may feel the need to seek outside work or to take on extra caregiving to their disabled sibling, in order to help with familial resources (Moore et al. 2002; Powell & Gallagher, 1993).

Eisenberg et al (1998) found that where the sibling resided did not significantly impact the overall family functioning because the SDI held a strong belief that where the disabled sibling resided, either at home or in residential accommodation, was the best place for them. The authors suggested this finding might be due to a cognitive dissonance effect, where the siblings positively adjust their thought patterns to the situation that suits them best. They did, however, find that the SDI were concerned about future caretaking responsibilities. The authors felt that open and honest familial communication could alleviate some of the sibling anxiety, rather than increase it. Overall, however, no support was found for increased psychopathology, adjustment problems or lowered self-esteem amongst the SDI (Eisenberg et al. 1998).

High levels of anxiety have been found in school-age SDI children, predominantly with autistic siblings, and this was associated with their sibling's disability (Powell & Gallagher, 1993). The SDI were often required to act as helpers for their disabled brother or sister, which could cause embarrassment. The SDI reported ambiguous feelings regarding the need to help or defend their disabled sibling versus wanting to conform to their peer group and consequent feelings of social stigmatization. It was also suggested that additional caregiving tasks for their disabled siblings might foster anxiety within some SDI (Turnbull & Turnbull, 1990).

1.2.4. Influence of interventions on emotional well-being for SDI

Parents of SDI express concern that non-disabled children miss out on normal activities and attention due to parental stress regarding the care of the disabled child (Dodd, 2004; Naylor & Prescott, 2004). However, attendance at support groups for SDI enables children to feel special and to discuss their feelings regarding their siblings with others in the

same position. Support groups can provide valuable time spent away from their disabled siblings (Dodd, 2004; Naylor & Prescott, 2004). Attendance at these groups can increase self-esteem and social support and encourage more positive coping strategies.

When the effect of formal social support, in terms of an early intervention programme for children of autistic spectrum disabilities (ASD) siblings, was examined, it was found that intervention resulted in fewer adjustment problems when the sibling was less severely autistic; however, increased severity of ASD resulted in a decreased protective effect from the intervention (Hastings, 2003b). The author noted that his sample had come from a highly socially advantaged background, which might have offered a degree of protection from adjustment disorders. This was in line with previous findings that indicated that higher socio-economic levels might play an ameliorating role for the SDI when faced with day-to-day issues concerning the disability (Stoneman et al.1988; Olsson & Hwang, 2008). Hastings further suggested that all siblings of children with ASD might be at a highly increased risk of developing adjustment disorders; he particularly suggested those whose siblings are more severely affected might be at an extreme risk of developing these disorders.

Family-based interventions can be used to promote understanding of the disabled sibling's condition, which should aid psychological adjustment (Lobato & Kao, 2005); particularly if lessons from the intervention programmes are reinforced by the parents. Conversely, sibling group attendance can be predictive of adjustment difficulties (Giallo & Gavidia-Payne, 2006); possibly because children who are already suffering from difficulties are more likely to be referred to intervention groups (Giallo & Gavidia-Payne, 2006). It is also argued that involvement with professionals can increase family stress; and that SDI meeting other children with disabled siblings could cause them to identify with negative aspects of the relationship with the disabled sibling and increase emotional difficulties (Rivers & Stoneman, 2003). However, it should also be noted that many of the 23 articles that have been reviewed on adult siblings (Davys et al. 2011) have called for intervention programmes to be implemented; while, most articles have a slightly different focus, the agreement seems to be on early targeted intervention and proactive planning for the future with the availability of counselling services if the siblings should so need. The necessity of early sibling involvement regarding future care-planning for the disabled sibling is re-iterated by Heller and Kramer (2009), who suggest that regardless of the level of care the sibling intends to give their disabled sibling, it is beneficial for all the family to be involved in the negotiations. It was suggested that the parents may not wish to include the SDI in talks

regarding the future as they do not want them to have a sense of obligation to take care of their disabled sibling, however, it was also found that when parents opinions are positive towards sibling involvement there is a much greater likelihood of the sibling agreeing to do be involved as a caregiver.

1.2.5. Impact of disabilities upon adult siblings

There has been a limited amount of research on the effect of disabilities upon adult siblings. Research that specifically examined adult siblings of ASD individuals showed a significantly higher prevalence rate towards depression than would be expected in the general population (Piven et al. 1990). However, Rossiter and Sharpe (2001) caution that while there may be differences in negative and positive affect in adult siblings, the current body of evidence is primarily anecdotal and therefore causal relationships cannot be assumed. Preliminary findings from a comparison of adult siblings of individuals with Down's syndrome (DS) versus ASD, noted that both groups had decreased contact with their disabled siblings as they got older; they also reported that the sibling of a person with DS scored higher on measures of health and lower on scores of depression than those whose siblings had ASD (Hodapp & Urbano, 2007).

Orsmond and Seltzer (2007a) matched adult siblings of ASD individuals with siblings of DS individuals and found ASD relationships with their disabled siblings were as contented as those who had DS siblings. This was measured through addressing direct questions regarding closeness and affection regarding their siblings. The siblings of ASD individuals were more concerned about their sibling's future and felt problems with their parents had arisen as a result of the ASD sibling. It was suggested that this could be due to most adult siblings growing up at a time when not so many disability services or education programmes were available. This can be more recently be explained through ASD individuals having higher service needs than DS individuals but not being able to access them as effectively (Esbensen, Bishop, Seltzer, Greenberg & Lounds-Taylor, 2010).

Seltzer, Orsmond and Esbensen (2009) compared adolescent siblings to adult siblings of ASD individuals. They found adults were less embarrassed about their disabled siblings and had less fear of social stigmatization than adolescents. They explained this by enhanced social skills and more adaptive use of social support. They suggested that coping strategies

varied between the groups with adults using more problem-focused strategies, which proved effective in buffering against the potential impact of negative behaviour from the ASD sibling. They also suggested that parental social support was important throughout the lifespan and could often enhance the relationship quality between the siblings. The authors proposed that a closer relationship between the siblings indicated a lower cut-off point for clinical depression at both adolescence and adulthood. They also reported that a combination of demographic factors, such as larger families, gender of the sibling with and without disabilities and age, could have an impact on adjustment, which supported the conclusions drawn by Macks and Reeves (2007). However, other research speculated that siblings of children with disabilities, particularly ASD, might be more at risk of developing affective disorder as they reached adulthood, possibly due to the intensifying impact of disability upon the family, including aging parents (Seltzer, Greenberg, Orsmond & Lounds, 2005). The authors suggested further research was necessary.

1.3 Anxiety and depression

1.3.1 Aetiology and effects of anxiety and depression

The relationship between stressful situations and the onset of anxiety and depression disorders has been extensively researched and there are considered to be strong associations and predictive values between these variables (Kendler, Kuhn & Prescott, 2004; Spinhoven et al. 2010). Anxiety and depression disorders are both classified under Axis 1 of the DSM-IV TR (Diagnostic and Statistical Manual IV), which means they can occur intermittently, that they tend to be quite complicated and are disorders with different potential aetiological causes (Trull & McCrae, 2005). There are numerous risk factors that can be shared between the disorders and these include adverse events in childhood, particularly emotional neglect from parents in the onset of depressive disorders (Spinhoven et al. 2010). Spinhoven et al found that the link between childhood adversities and affective disorders was greater than the link between lifespan negative episodes and affective disorders and that negative events in childhood were a feature of lifetime depression and anxiety disorders. However, a cyclical effect has also been suggested, whereby anxious children might perceive more negative events or behave in a manner that means they are more likely to experience more negative life events (Allen & Rapee, 2009).

Individuals with anxiety often experience a constant sense of nervous anticipation, worry, insomnia, irritability and a lack of concentration; often coupled with physiological symptoms such as 'butterflies' in the stomach, sweating and pounding hearts (Mind, 2008). This can result in a decreased ability to work, which can then lead to poor economic outcomes and social impairment. Anxiety sufferers also tend to make increased use of health services (de Beurs et al. 1999). The state of heightened affective negative arousal is contrasted with the lowered capacity of depressed individuals to experience arousal due to their tendency to be subdued (Watson, Gamez & Simms, 2005). Depression sufferers might additionally suffer from extended periods of dysphoria, loss of self-confidence and self-esteem, feelings of hopelessness and being helpless to do anything about it, and an overwhelmingly pessimistic outlook (Mind, 2008). It increases the risk of experiencing medical illness and thereafter complications. In more extreme cases of depression the individual might experience thoughts of self-harming or even suicide. There is often a pervasive co-morbidity of anxiety and depression, which can significantly increase the symptoms (Norberg, Diefenbach & Tolin, 2008; Roy-Byrne et al. 2008), and which can be extremely debilitating.

A meta-analytical report of generalised anxiety and major depression disorders aetiological causes included socio-demographic features, parenting styles, stressful life events, personality traits and social support; these factors were particularly important in influencing depression. It was also proposed that genetic factors were potentially influential in the onset and maintenance of anxiety and depression (Hettema, 2008).

Anxiety and depression can be psychologically costly to the individual involved and can create further tensions and problems for their families. Psychological interventions to treat people with these psychopathological disorders can also be very costly but when consideration is paid to the costs to society when someone suffers, in terms of inability to work, increased medical utilisation, prescription drugs and disability state pay-outs (Donovan & Spence, 2000; Farrell & Barrett, 2007) it is an issue worth trying to tackle at the level of potential root causes.

1.3.2 Aetiology and effects of anxiety and depression on siblings of disabled individuals

A study conducted on 67 adult siblings of disabled individuals, who had a mean age of 33, found 15% had received treatment for depression (Piven et al. 1990); this was significantly higher than the 3% rates that epidemiological studies had suggested was the prevalence of the general population towards depression (Olfson et al. 2002). It should be noted that the Piven study was specifically looking at siblings of autistic individuals, which might have had an effect. However, a meta-analytical report on SDI in childhood also found a small but significant prevalence towards affective disorders in this group (Rossiter & Sharpe, 2001). Likewise, numerous studies have warned of the higher risk of affective disorders that was prevalent within these siblings and have stressed the necessity for further research of the siblings as adults (Giallo & Gavidia-Payne, 2006; Moore, Howard & McLaughlin, 2002; Ross & Cuskelly, 2007; Seltzer et al. 2009).

1.4 The effects of demographic variables upon sibling disability

1.4.1 Gender

Research has found that females are more likely to report anxious and depression symptoms, suggesting that there might be earlier-onset anxiety in females, which, given the co-morbidity of the disorders (Norberg et al. 2008; Roy-Byrne et al. 2008) might help to explain the higher female propensity to major depression when they are older (Breslau, Schultz & Peterson, 1995; World Health Organisation, 2010). Women are twice as susceptible as men to experience depressive symptoms (Nolen-Hoeksema, 2001). However, this might be explained by men's reluctance to admit to mental health problems (Winkler, Pjrek & Kasper, 2006), and due to them not seeking help for these issues; this could explain their higher successful suicide rates than females (Bjerkeset, Romundstad & Gunnell, 2008; Oliffe & Phillips, 2008). However, it has also been suggested that there is no general female propensity towards depression but that the greater reporting of depression by females is due to their greater predisposition towards anxiety (Parker & Hadzi-Pavlovic, 2001). This might be due to women experiencing greater hormonal fluctuations, particularly throughout childbearing years. It could also be due to the role of recall, whereby females tend to dwell more on interpersonal events in the development of depression when compared to men (Wilhelm, Roy, Mitchell, Brownhill & Parker, 2002).

Sisters are reported to play a larger part than brothers in their disabled sibling's caretaking (Crnic, Friedrich & Greenberg, 1983; Cuskelly, Chant & Hayes, 1998; McHale & Gamble, 1989; Rossiter & Sharpe, 2001; Stoneman et al. 1988) and consequently it had been expected for there to have been a larger effect upon them; however, no gender differences in affective disorders were found when compared to a normative sample in a meta-analytical report (Rossiter & Sharpe, 2001). However, Stoneman et al. (1988) found that older sisters of disabled individuals had increased responsibilities, particularly in less affluent families; the increased caregiving could result in feelings of anger and resentment towards the family. A further study found an association between increased caregiving towards Down's syndrome siblings by sisters and elevated rates of anxiety and depression (Cuskelly et al. 1998). It was also reported that due to caregiving responsibilities, older sisters of disabled children experienced a decreased amount of social activities and events outside the home in comparison to their peers and this resulted in increased conflict with their parents and increased anxiety (Crnic et al. 1983). Research has found that SDI spent more time in caretaking activities and again that sisters spent more time caregiving but, to put it in perspective, it was suggested that sisters undertaking more caregiving responsibilities at home was a reflection upon society generally (McHale & Gamble, 1989).

McHale and Gamble (1989) did, however, find that brothers with disabled siblings spent as much time caregiving as sisters with non-disabled siblings. The study also found that the SDI had more negative interactions with mothers and that sisters performed more poorly on almost every aspect of adjustment but they were still found to be outside the clinical range for anxiety and depression. Siblings who were older than the disabled brother or sister scored lower on their self- perception, social acceptance and personal satisfaction than the control group. The authors suggested that growing up with a disabled sibling and the potential psychological distress might be predictive of future affective difficulties in adulthood (McHale & Gamble, 1989). Other research has generally agreed with McHale and Gamble when a study on children whose siblings have autism found that the siblings showed poorer adjustment, specifically in domains such as 'peer problems' and 'conduct problems'. In contrast to McHale and Gamble though, brothers of autistic siblings showed poorer adjustment and that those who were older than their disabled sibling exhibited better adjustment than those who were younger (Hastings, 2003a). Further research found more school problems for brothers of disabled children, whereas sisters were more likely to score higher on affective disorders (Hannah & Midlarsky, 1999).

1.4.2 Age

As already noted, childhood adversities can play a significant role in the onset, development and maintenance of anxiety and depression (Spinhoven et al. 2010). However, research has indicated a decline in symptoms of anxiety and depression as an individual becomes older (Henderson et al. 1998). Negative and stressful life events in adulthood could, however, be related to the beginning of major depression disorders (Kendler et al. 2004) and to a lesser extent to the onset of anxiety disorders. Anxiety disorders tend to be less widespread amongst adults aged over 65, in comparison to younger adults (Lynch, Comptom, Mendelson, Robins & Krishnan, 2000). However, when they occur they can be of a particularly serious nature. Other findings show that anxiety decreases with age (Byers, Yaffe, Covinsky, Friedman & Bruce, 2010). While there remained a high occurrence in disorders, particularly amongst women, there was a steady decline in occurrence of the disorder due to age: 16.6% of participants between 55 and 64 years suffered with anxiety symptoms compared to 8.1% over the age of 85 (Byers et al. 2010).

Stress-related younger onset of depression seems clinically different to late onset elderly depression (Lynch et al. 2000). In a sample of clinically depressed geriatric patients there was no evidence of an age effect for anxiety. However, older subjects had lower scores on subjective depression, interpersonal sensitivity and hostility in comparison to younger subjects (Alexopoulos et al. 1995).

1.4.3. Relationship satisfaction

Marital satisfaction is an established factor in emotional well-being, both for the married couple and any children that they might have (Amato & Cheadle, 2005). However, conversely, marital dissatisfaction, divorce or separation is highly associated with depression and anxiety. It has been suggested that the relationship between marital breakdown and anxiety and depression could be bi-directional (Bulloch, Williams, Lavorato & Patten, 2009).

Anecdotal evidence exists that the divorce rate of parents of children with disabilities could be as high as 80% (Richardson, 2008); this is in comparison with the national figures whereby approximately 45% of marriages end in divorce (Wilson & Smallwood, 2005). Parental divorce can often have an impact on the emotional well-being on the couple's children (Amato & Cheadle, 2005).

1.4.4 Socio-economic status

There are higher prevalence rates for anxiety and depression in people classed within the lower socio-economic bands; further, this appears to be a cross-cultural phenomenon and applies to all age-groups (Anli & Karsli, 2010; Butterworth, Rodgers & Windsor, 2009). Families with disabled children often suffer downward social mobility due to one of the parents (usually the mother) having to relinquish employment due to the additional care that the disabled child requires; this, alongside the increased costs of care for the disabled child, would result in reduced finances and have an adverse effect upon the familial social-economic status (Emerson, Hatton, Llewellyn, Blacher & Graham, 2006). Additionally, the familial economic downturn could also be attributed to the increased risk of poorer maternal well-being due to the extra stressors involved in caring for a disabled child (Eisenhower & Blacher, 2006). Research has shown that SDI from advantaged socio-economic positions tended to have better adjustment patterns than those from lower-socio-economic backgrounds. This might be due to them being better able to access and benefit from different intervention programmes (Hastings, 2003b).

1.4.5 Educational attainment

A growing body of research indicates higher levels of educational attainment can act as a protective factor against anxiety and depression (Bjelland et al. 2008; Gale, Hatch, Batty & Deary, 2009); this is thought to have a cumulative effect as the individual ages (Bjelland et al. 2008). Gale et al (2009) gave potential suggestions as to why this might be the case. Initially they proposed that having a higher IQ meant it was less likely that the individual would experience socio-economic disadvantage, which, as discussed, is a known factor in anxiety and depression. They also suggested that those with a higher IQ tended to react more flexibly to stressors through finding different ways to cope. Having a higher internal locus of control is often a protective factor against affective disorders (Gale et al. 2009) may also be

determined by a higher IQ. They also considered that higher intelligence might act as a defensive mechanism in those genetically predisposed to affective disorders.

However, parents of children with disabilities have raised concerns that due to the behaviours of the disabled child, such as high noise levels and disruptive behaviours, their child without disabilities might experience broken sleep patterns. There was worry that this could potentially have an adverse effect on the educational progress of their child without disabilities (Banks et al. 2001; Dodd, 2004).

1.4.6 Variables exclusive to the SDI

Previous research has shown no evidence of increased rates of affective problems due to whether or not the sibling with disabilities lived at home, as long as the sibling without disabilities believed that their sibling was in the best accommodation suitable to their needs (Eisenberg, Baker & Blacher, 1998). However, it was also found that despite conflict in the home being lessened, the siblings were not as close once the disabled one had been placed in a residential setting (Eisenberg et al. 1998). This concept could benefit from further investigation, as it might be that because the child was not the primary caregiver there were not as many emotional consequences; however, the point of interest would be if there was any change in the affective dynamics if the disabled sibling assumed residence with, and care needs from, the adult SDI.

It has been suggested that amongst other factors, the severity of the disability should be taken into account when examining for anxiety and /or depression in siblings of the disabled (Rossiter & Sharpe, 2001). All siblings of children with autism might be at an increased risk of incurring adjustment disorders; and these disorders can become more pronounced the more severely the sibling is affected by autism (Hastings, 2003). However, Sellinger, Hodapp & Dykens (2006) have suggested that as some individuals with PWS age (autism, per se, was not examined in this paper) their behaviour becomes less maladaptive. This might have a beneficial effect upon all the other family members and make contact with their disabled sibling less stressful for the siblings (Seltzer et al. 2009).

Conflicting evidence exists with regard to the birth order of a child and also if a large number of siblings are beneficial for the SDI or not. Large families often mean less parental time for the children and increased economic hardship. In larger families they found that later

born children had an advantageous effect on mental health, whilst conversely older children are often associated with emotional difficulties (Lawson & Mace, 2010). A meta-analytical report found mixed results regarding anxiety; some studies suggested that the first-borns were more anxious and fearful, whilst other studies found no birth order difference at all (Adams, 1972). There was also a suggestion that first-borns were more dependent, displayed higher conformity and had a greater sense of responsibility than those who were born later, but again the studies were inconclusive (Adams, 1972).

Siblings younger than the disabled child can display immature and attention-seeking behaviour, as a response to the disproportionate amount of parental care received by their disabled sibling (Tew & Lawrence, 1973). Conversely, better adjustment patterns were found in older siblings who had spent time living within a 'normal' family environment before the birth of the disabled child. However, no significant effect was found in the Tew and Lawrence study as a result of birth order. Male siblings, as children, who were younger than the disabled sibling, were more likely to experience anxious and depression symptomatology (Breslau, 1982). However, the conclusions drawn from Breslau's study was that, as adults, females were more likely to display anxious and /or depression tendencies, whereas males were more likely to demonstrate interpersonal aggression.

Other research has raised concerns from younger SDI regarding overtaking their older disabled siblings either academically or physically (Turnbull & Turnbull, 1990). Younger siblings might consequently suppress negative feelings regarding their disabled sibling due to guilt (Stoneman, Brody, Crapps & Malone, 1991). Conversely, Lobato, Miller, Barbour, Hall and Pezzullo (1991) proposed that positive feelings towards their disabled sibling might be due to younger siblings witnessing increased maternal nurturing, which other research suggested might have become ingrained into the child (Brody, Stoneman, Davis & Crapps, 1991). However, in contrast, Gold (1993) suggested that, due to extra caregiving responsibilities, SDI were more likely to have elevated rates of anxiety and depression and this particularly applied to younger siblings. Conversely, Levy-Wasser and Katz (2004) found no difference in adjustment patterns between older and younger siblings.

1.5. Factors that could impact upon SDI well-being

1.5.1. Perceptions of parenting styles and childhood attachment styles

Research has shown that childhood experiences are fundamental in the development of personality and attachment styles (e.g., Bowlby, 1991). This will necessarily include relationships with family, and particularly influential at a young age, are parents. Bowlby's (1982, 1973, 1980) attachment theory, stated that the relationship between primary caregiver and infant was key to the development of the child's inner representations of models of the self and of others; this included developing strategies whereby thoughts and feelings of attachment figures could be processed. Whilst the majority of children have positive experiences and follow a secure and happy path; if adverse or difficult events happen within the family there is a higher risk of negative emotional outcomes (Bowlby, 1982, 1973, 1980; Rosenman & Rodgers, 2006). This could lead to the perception of sub-optimum parenting styles, which can have significant associations with insecure attachment and higher levels of anxiety and depression symptomatology (Bifulco et al. 2006; Hinnen, Sanderman & Sprangers, 2009; Mikulincer & Shaver, 2007). The parents of children with disabilities might necessarily have had to divert more of their time and attention to the disabled child (Moore et al. 2002; Powell & Gallagher, 1993; Rossiter & Sharpe, 2001) leaving the child without disabilities at potential risk of perceiving the parents as acting inconsistently towards them as the parents were perhaps not always able to give their non-disabled children priority.

Attachment theory was initially conceptualized as a model of development that acknowledged that psychopathological tendencies could develop if normative paths for the individual were not followed (Bowlby,1982, 1973, 1980). Bowlby considered that maladaptive behaviour often had its roots in the early relationships that were formed between infants and primary caregivers. Caregivers are intrinsically expected to be loving, available and attentive to the child's needs and when this system of caregiving is not available, or is inconsistent, it can lead to maladaptive attachment styles, manifesting in lower conceptions about intrapersonal regulation and less positive beliefs about interactions with others (Mikulincer & Shaver, 2007). Different attachment styles are proposed to influence the development of internal working models of the view of the self and of others, which become central characteristics of personality (Bartholomew & Shaver, 1998), where they continue to influence cognitive, affective and behavioural patterns (Bowlby, 1973, 1980, 1982; Collins, Cooper, Albino & Allard, 2002). Attachment theory is important in helping to understand the lasting impact that childhood events can have on adult life. Bowlby proposed that if attachment patterns were negatively modified, the child could then potentially become vulnerable to affective disorders.

A series of longitudinal studies on the stability of attachment patterns from infancy to late adolescence found overall that attachment types are relatively constant over time, particularly in middle-class families who have experienced only a few negative life events (Waters et al. 2000b), and when change did occur it was usually because of environmental factors (Waters et al. 2000a). Hamilton (2000) also found relatively consistent patterns of attachment in her study of children from non-conventional families and proposed that negative life events appeared primarily to emphasise insecure infant attachment trajectories, thus suggesting a continuity of style, particularly if negative events occurred early in life. She further proposed that infants with secure attachment were more resilient to life stressors. However, Weinfeld, Sroufe and Egeland (2000) cautioned against this and proposed that continuous life stressors might take their toll and thus continuity of the secure classification cannot be guaranteed. Their sample was from a high risk environment, and they found little continuity of attachment style and suggested this was due to the instability of both environment and caregiving relationships.

Secure attachment develops as a result of warm, responsive, sensitive parenting; consequently the child feels safe in the knowledge of the parental 'safe haven' at times of insecurity, and the child then develops a positive internal working model of the self and others (Ainsworth, Blehar, Waters & Wall, 1978; Steele, 2002; Waters et al. 2000a). Characteristics of secure childhood attachment include confidence and a developed sense of autonomy (Solomon & George, 2008). They will usually react to adverse situations in a constructive manner, viewing solutions in a realistic way and expecting straightforward outcomes (Shaver & Mikulincer, 2002).

Insecure attachment can be represented dimensionally as either an attempt to minimize (attachment-related avoidance) or maximize (attachment-related anxiety) attachment needs, dependent upon the way the child interprets the best strategy to make the most of the potential caregiving available. When the child minimizes their attachment needs they defensively distract themselves by removing themselves emotionally from the distress that caregiver unavailability may cause; however, this tends to have enduring long-term effects, as they learn to conceal their suffering even from themselves, therefore being unable to have true access to their inner feelings (Dozier, Stovall-McClough & Albus, 2008; Greenberg, 1999). In attachment terms the development of the minimizing style of attachment defence will lead to the development of attachment-related avoidance, where the individual will question how comfortable they are with intimacy and dependency within a

relationship (Bartholomew & Horowitz, 1991; Griffin & Bartholomew, 1994; Noftle & Shaver, 2006; Shaver & Brennan, 1992). The parenting styles of children who develop attachment-related avoidance tend to be rejecting, distanced and uncomfortable with physical closeness. Furthermore these parents also have a tendency to withdraw at times of the child's emotional distress in the child (Ainsworth et al. 1978; Edelstein et al. 2004). The child consequently learns that a suppressed response is the most appropriate course of action for them.

In contrast, when a child maximizes their attachment needs they defensively turn their attention inwards and become distressed due to a perceived lack of caregiver availability; the child becomes so preoccupied with the caregiver relationship that it is then unable to clearly delineate whether the caregiver is actually helping or not and also if there is a genuine threat to be protected from (Dozier et al. 2008; Greenberg, 1999). The development of the maximizing strategy measures the view of self or attachment-related anxiety, where feelings of rejection, abandonment and self-worth are fundamentally absorbed (Bartholomew & Horowitz, 1991; Griffin & Bartholomew, 1994; Noftle & Shaver, 2006; Shaver & Brennan, 1992). Ainsworth et al (1978) found that parents of children with attachment-related anxiety tend to be marked by inconsistent and often intrusive interactions with their children. They have a tendency to put their own needs ahead of the child's and thus the child is uncertain if an attempt for comfort would gain a positive response, which results in ambivalent behaviour (Rholes et al. 1998). However, a study by Crowell and Feldman (1991) suggested that this childhood anxiety might be caused by the parental difficulty in separating from the child.

High levels of attachment-related avoidance and anxiety result in disorganised attachment, which is manifested in a small but significant amount of children who display conflictual and erratic attachment behaviours (Lyons-Ruth & Jacobvitz, 2008). The parents of children with disorganised attachment might help to exacerbate the style, due to them having failed to address attachment issues of their own and, therefore, insecure attachment is passed from one generation to the next. It is important to note that disorganised attachment is the one that is most prevalent in predicting a wide range of maladaptive psychopathological outcomes (Bernier & Meins, 2008; Dallaire & Weinraub, 2007; Lyons-Ruth & Jacobvitz, 2008).

Either of these attachment-related avoidance or attachment-related anxiety strategies can result in the development of affective disorders as the child who minimizes is diverting the attention away from the self, without any resolution of the hurt he feels that is caused by

others and thus can develop externalising disorders, such as behavioural problems, until his inner conflict has been dealt with. The child who develops maximizing strategies, which focuses attention upon the lack of caregiver availability and then reflects negatively upon the self as the reason for this happening is at an increased risk of developing internalising disorders, such as anxiety and/or depression until the negative view of self can be resolved.

Importantly, the child's perceptions of parental responsiveness and the consequent mental representations that are developed are based on actual, not imagined, experiences (Bretherton, 1992). These theories have been extensively empirically investigated and there is now considerable clinical evidence that the development of insecure attachment styles could result in vulnerabilities towards affective disorders, such as anxiety and depression (Mikulincer & Shaver, 2007).

1.5.2 Attachment influences on child psychopathology

Considerable evidence has accumulated that has indicated that early dyadic attachment security with a primary caregiver, usually the mother, serves as a protective influence against the development of affective symptoms (Dallaire & Weinraub, 2007; Deklyen & Greenberg, 2008; Greenberg, 1999). This might, in part, be due to the way securely attached individuals rationally attend to anxiety provoking information from the environment as opposed to the more fearful approach adopted by insecurely attached individuals (Van Emmichoven, Van IJzendoorn, De Ruiter & Brosschot, 2003). A longitudinal study by Dallaire and Weinraub (2007) found that attachment security, when children were as young as 15 months, protected children against developing anxiety even when the family experienced stressful and negative life events; which supported Bowlby's (1973) claim, whereby early secure attachment specifically safeguards children from developing anxiety. DeKlyen and Greenberg (2008) suggested that children who have attachment-related anxiety were more likely to develop affective disorders, such as anxiety and depression, whereas children with attachment-related avoidance were more likely to develop externalising or behavioural problems. They also argued that insecure attachment in itself is not sufficient cause for a psychopathological trajectory to occur but should certainly be considered a risk factor.

Further research has shown consistent relationships between childhood attachment-related anxiety and later anxiety disorders. Warren, Houston, Egeland and Sroufe's (1997) findings suggest that attachment-related anxiety in infants could significantly predict the development of later anxiety disorders; however, they also suggest that child temperament could play a contributory factor. Likewise, the findings from a study by Nakash-Eisikovits et al. (2002) suggest that secure attachment is negatively associated with psychopathology, whereas attachment-related anxiety is highly related to withdrawal, introversion and internalisation. Rosenstein and Horowitz (1996) also found that children categorised as preoccupied were more likely to suffer from affective disorders, including self-reported anxious and dysthymic personality traits, whereas dismissing children were more likely to have antisocial, conduct and substance abuse disorders. They concluded that the results support the view that developing psychopathology was partially based on relationship experiences with parents.

Evidence indicates that childhood experiences are pivotal in the development of personality and attachment styles (Bowlby, 1991). Wearden et al (2008) found that once negative affect had been controlled for, inconsistent maternal caregiving was associated with attachment-related anxiety, but only for females. They further found that inconsistent mothering was weakly associated with negative core beliefs about the self, but again this finding was only for females, whereas warm paternal caregiving was associated with positive feelings towards others. Carnelly et al. (1994) found consistent indicators that negative relationships with parents, particularly mothers, increased the reporting of depression symptoms. Further evidence also indicates that sufferers from Generalised Anxiety Disorder were more likely to report attachment-related anxiety childhood experiences, which included feelings of not being loved sufficiently and feelings of maternal neglect and/or rejection, and also insecurely attached current states of minds (Cassidy, Lichtenstein-Phelps, Sibrava, Thomas Jr. & Borkovec, 2009). Again, this vulnerability finding particularly applied to females in relation to their mothers. These studies support the argument that ineffective caregiving by parents could result in insecure attachment, which in some instances could perpetuate tendencies towards later psychopathological problems (Brennan & Shaver, 1998).

1.5.3 Birth order and attachment style

The birth order position of the child might also play an important function in the development of attachment style and possible propensities towards affective disorders. Hauenstein (1990) contended that parents may be overly concerned with the child with special needs and consequently not be as available to attend to the needs of younger siblings. Conversely, another study that examined SDI as children, found that their rates of adjustment were similar to the control group; however, there was a higher tendency for the SDI group to have secure attachment styles in comparison to the control group (Levy-Wasser & Katz (2004). Further, they found no significant difference between whether the sibling was younger or older than the disabled brother or sister in either attachment style or emotional adjustment. In contrast, Boyce and Barnett (1993) argued that the greater burden imposed upon older siblings of disabled individuals, due to perhaps having to step in as carers, would have a negative adjustment effect. However, Friedlin and Florian (1996) asserted that older siblings would have had the benefit of their parents' full attention before the disabled sibling came along and this would act as a protective factor. Older siblings could have experienced the positivity of witnessing a caring family situation and this would benefit long-term adjustment.

1.6 Adult attachment

1.6.1 Adult attachment styles

Attachment theory is an interpersonal model and consequently it measures the self as it is reflected through others, both 'objectively' and 'subjectively' (Noftle & Shaver, 2006, p.180). It has been proposed that adult attachment is a dynamic continuation of infant attachment, reflecting the same behaviours, cognitions and emotions, but with a partner replacing the role of the primary caregiver in providing security, physical comfort and potentiality as a good caregiver (Kirkpatrick, 1998; Waters, Hamilton & Weinfeld, 2000a; Waters, Merrick, Treboux, Crowell & Albersheim, 2000b). Securely attached adults tend to report positive relationships within their family upbringings (Diehl, Elnick, Bourbeau & Labouvie-Vief, 1998). In contrast, adults with attachment-related anxiety recall low levels of parental warmth and support. In addition, significant associations exist between inconsistent parental care, overprotection and conflictual family circumstances (Heinonen, Raikkonen, Keltikangas-Jarvinen & Strandberg, 2004). It has been suggested that absent and /or unresponsive parenting might be the reason for the development of the adult attachment-

related avoidance style (Shaver & Mikulincer, 2005). Further studies support this and suggest that insecure adult attachment can be explained through childhood familial conditions (Hinnen, Sanderman & Sprangers, 2009). Hinnen et al (2009) concluded that attachment styles could act as a mediator between childhood memories and adult life satisfaction. They found that warm, loving parenting was associated with secure attachment and adverse parental events in childhood lead to insecure attachment; those who were securely attached were significantly more satisfied with their adult life than those who were insecurely attached. Bifulco et al (2006) also suggested that insecure adult attachment could act as a mediator between adverse childhood events and the development of affective disorders such as anxiety and depression.

A series of previous studies have argued for a continuity of attachment style between childhood and adulthood; this particularly tends to occur when events remain fairly stable over the life-course (Hamilton, 2000; Waters, Hamilton, & Weinfeld, 2000; Waters, Merrick, Treboux, Crowell, & Albersheim, 2000; Waters, Weinfeld & Hamilton, 2000). However, it should be noted that continuity of attachment style should not be taken for granted and different trajectories (both positive and negative) can be expected if there is dramatic change or instability in life (Mikulincer & Shaver, 2007; Shaver & Mikulincer, 2008; Weinfeld, Sroufe & Egeland, 2000). Anxious attachment measured through the model of self in childhood can be a significant predictor of the development of later anxiety disorders (Greenberg, 2008; Warren, Houston, Egeland & Sroufe, 1997).

The 'model of self', measured dimensionally as attachment-related anxiety, is an intrinsic, dimensional view as to how worthy of love and respect from others the individual feels; whereby acceptance is paramount and there is a dependency on a partner's approval. Conversely, the 'model of other', measured dimensionally as attachment-related avoidance, is the view as to how reliable and supportive a partner will be and this will indicate the extent to which the individual will accommodate or avoid a partner (Bartholomew & Shaver, 1998; Klohnen & John, 1998). As Figure 2.1 shows, the four categories that are extrapolated from this two dimensional system are dependent upon negative or positive models of 'self' and 'others'.

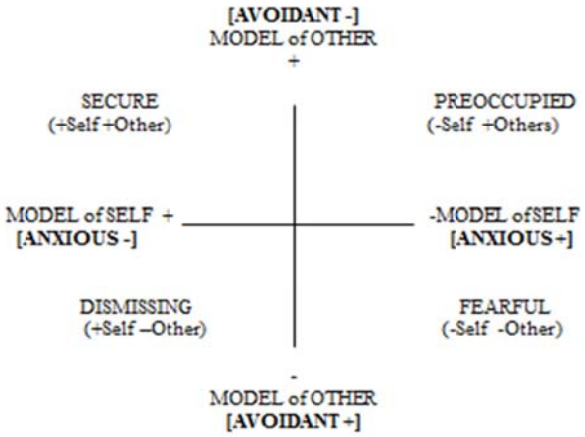

FIGURE 2.1: Adapted from the two-dimensional, four category adult attachment model (Bartholomew & Horowitz, 1991; Klohnen & John, 1998)

Briefly, securely attached individuals are characterised by a positive 'model of self' and 'others' (Bartholomew & Horowitz, 1991) and they have low scores on both the anxious and avoidant dimensions (Brennan, Clark & Shaver, 1998). They have a belief in the good motivations of others; consequently, any negative behaviour from the partner will be treated with 'functional' anger, in order to maintain constructive, stable and intimate relationships (Shaver & Mikulincer, 2002). Due to these autonomous individuals' capability of being honest with themselves and others, even under adverse attachment conditions, it perpetuates a more exact self-knowledge (Gjerde, Onishi & Carlson, 2004), which allows problem solving to be based in reality (Bretherton, 1992). They engage in pro-active, adaptive problem solving, due to their own secure behavioural systems (Collins & Read, 1990; Griffin & Bartholomew, 1994; Hollist & Miller, 2005; Shaver & Mikulincer, 2002). It is postulated that the more secure a person is, the more predictable their behaviour will be (Waters et al. 2000b).

In contrast to those who are securely attached, individuals who score highly on the anxious dimension tend to have attachment systems that are constantly hyper-activated (Mikulincer & Shaver, 2005) and as a consequence they tend to be hyper-vigilant as a defence against real and imagined potential interpersonal threat (Mikulincer & Shaver, 2007;

Simpson & Belsky, 2008). They tend to be unable to accept support or derive benefits from others as they are constantly aware of any real or imagined negative behaviour their partner displays, which can counteract the support they are receiving (Simpson, Campbell & Weisberg, 2006). Further, the distress of any perceived threat continues to disturb the anxiously attached individual even once the stressor has gone (Mikulincer & Shaver, 2007).

There is a tendency for anxiously attached individuals to crave the intimacy of a close relationship, but because they feel unworthy of love they often then tend to display dysfunctional relationship behaviours (Klohnen & John, 1998) but still have a strong need for acceptance from others (Collins et al. 2002). There is a further tendency for them to focus excessively on both their partner's and relationship based problems, but as they intrinsically believe their own needs are not being fulfilled by their partner, their care towards them is particularly inconsistent, vacillating between smothering and neglectful (Carnelly, Pietromonaco & Jaffe, 1996; Nakash-Eisikovits, Dutra & Westen, 2002). If the partner does not then give the required reassurance, the anxiously attached individual can have feelings of despair (Feeney, 1998), which can then create an increased tendency to plummet into depression (Brennan & Shaver, 1998). This can be further exacerbated through their tendency to validate themselves through their partner's responses (Nakash-Eisikovits et al. 2002). High levels of attachment-related anxiety can be categorized as preoccupied attachment, which is where an individual has a low model of self but a high model of others (Bartholomew & Horowitz, 1991; Brennan et al. 1998).

Individuals high on the avoidant dimension have a tendency to be excessively independent and consequently to deny any attachment needs (Feeney, 1998). They try to negate the necessity for close involvement with others, usually as a subliminal defensive method against unfeeling responses from others (Carver, 1997; Gjerde et al. 2004). Socialising is usually activity based, or superficial, where there is no deeper sharing of thoughts or emotions (Gjerde et al. 2004). Avoidantly attached individuals will tend to lack self-honesty as they view their behaviours as 'normal' and have a propensity to self-idealise. Findings indicate this may be due to parents who disapproved of any form of negative affect (Henry & Holmes, 1998). This is in contrast to other research that indicates avoidantly attached people will actually create social and cognitive surroundings that will keep their attachment system deactivated (Fraley, Davis & Shaver, 1998; Shaver & Mikulincer, 2002). Attachment-related avoidance can be categorized as dismissive attachment, which is where

an individual has a high model of self but a low model of others (Bartholomew & Horowitz, 1991; Brennan et al. 1998).

Individuals who have a combination of high anxious and high avoidant dimensional scores are categorized under the fearful attachment category; whereby an individual has a low model of self and others (Bartholomew & Horowitz, 1991; Brennan et al. 1998). There is a breakdown in the degree of trust they have in others and consequently they find it difficult to depend upon others for emotional support in times of distress (Feeney, 1998; Rholes, Simpson & Stevens, 1998). There is a further acute concern of rejection (Feeney, 1998), which is constantly anticipated (Bartholomew & Shaver, 1998). They tend to seek to cope on their own without relying on others for social support, which they feel would not be forthcoming. However, they are reliant upon others' approval and acceptance for self-validation (Bartholomew & Shaver, 1998).

1.6.2 Adult attachment vulnerability to psychopathology

Attachment style has been proposed to be a significant indicator of emotional resilience or vulnerability (Bowlby, 1982). There are consistent findings between insecure attachment, particularly a low model of self and an increased propensity towards depression (Murphy & Bates, 1997; Reis & Grenyer, 2004).This was postulated to be due to "intra and interpersonal regulatory deficits" (Mikulincer & Shaver, 2007, p.369) that have arisen as a result of neglectful, inattentive, unavailable or rejecting caregivers, which are consolidated over time. This has the effect of leaving an individual prone to low self-worth and self-efficacy; they are consequently more likely to absorb criticisms and dissatisfaction, leaving them vulnerable to rejection and distress. These are prime conditions for the development of affective disorders (Beck & Emery, 1985; Mikulincer & Shaver, 2007). Reis and Grenyer (2004) further postulated that attachment-related anxiety, which includes the preoccupied and fearful types, would be particularly prone to lower-level, sub-clinical depression symptoms, whereas those who are specifically fearful would be more vulnerable to major depression disorders, due to them simultaneously viewing themselves negatively and others as rejecting and hostile. They further suggested that women who are susceptible to attachment-related anxiety are also more prone to develop depression symptoms and that these tendencies are more likely to be maintained due to them not fully engaging in therapy processes. Dozier et al (2008) postulated that the manifestation of affective disorders, especially anxiety, would be

associated with hyper-activating strategies of the anxious dimension, as individuals sought to maximize their attachment requirements; whereas attachment-related avoidance would much more likely manifest in externalizing disorders, as the individuals seek to minimize or deactivate their attachment needs.

The hyper-activating tendencies of individuals with attachment-related anxiety tends to heighten deep and long-lasting distress, which persists even as the stressor has considerably weakened; this can become cyclical and self-fulfilling and can result in poor emotion-regulation and decreased ability to deal with day-to-day issues. This might leave these individuals more vulnerable to the affective disorders of anxiety and depression (Mikulincer & Shaver, 2007). A further suggestion was made by Mikulincer and Shaver whereby there was a difference in depression symptoms between attachment-related anxiety and attachment-related avoidant individuals, with the former reporting interpersonal deficits such as overdependence, lack of autonomy and clinginess resulting in depression, whereas the latter were more likely to report achievement-related problems, such as self-criticism and unrealistic and unsustainable perfectionistic aims that when unachievable would often result in depression symptomatology (Mikulincer & Shaver, 2007; Murphy & Bates, 1997). However, as individuals develop they may alter their attachment styles for the better (Pearson, Cohn, Cowan & Cowan, 1994) or to their detriment (Rothbard & Shaver, 1994) as a result of the influence of other interpersonal relationships.

1.7 Personality traits

1.7.1 Big Five personality traits

Personality researchers have suggested that personality can be meaningfully broken down into five relatively orthogonal categories, known as the Big Five (Goldberg, 1992). The five dimensional factors are represented in the following ways: extraversion, agreeableness, conscientiousness, neuroticism/ emotional stability and openness to experience (hereafter openness); these are a hierarchically organized system of lexical descriptions of personality, with these phenotypic trait-descriptors as the higher order factors (Goldberg, 1993). It was proposed that these personality traits extend beyond basic temperament to include thoughts, values and attitudes and thus indicate a high level of predictive validity (Evans & Rothbart, 2007).

It has been suggested that personality traits are endogenously based and consequently show high levels of stability and hence predictability over the lifespan (McCrae, 2002; McCrae et al. 2000). The American Psychiatric Association (DSM IV - 1994) has indicated that personality traits are indicative of constant and persistent behavioural patterns that are in evidence from young adulthood. However, other research suggests reasonably consistent changes in personality traits over the lifespan; this applied to the individual factors that could develop at different life stages. It may be that the lifetime plasticity of personality traits could be attributed to broader life experiences (Edmonds, Jackson, Fayard & Roberts, 2008; Srivastava, John, Gosling & Potter, 2003). Furthermore, Gow, Whiteman, Pattie & Deary (2005) also suggest that age and gender differences should be taken into account when analysing data due to normative developmental changes in personality traits throughout the lifespan. They demonstrated consistently different effects over three groups, with females showing higher levels of agreeableness and neuroticism but reporting lower intellect mean levels; their study also showed consistent changes in all the five factors due to differential age effects; agreeableness and conscientiousness levels rose over the lifespan, whereas emotional stability (versus neuroticism) rose towards late adulthood (i.e. neuroticism levels fell) and extraversion and intellect levels fell towards late adulthood.

It has been suggested that personality traits have a fundamental temperamental basis, which indicates genetic predispositions towards certain traits and that automatic responses to situations occur as a result of this (Clark & Watson, 1999). Controversy surrounds the impact of the situation, with some researchers arguing that personality traits are inherent and are little affected by situational factors, suggesting that adverse events would have little bearing on the development of personality (McCrae et al. 2000). In support of this view, it has been shown that early indicators of the Big Five dimensional factors appear early in life, even before social indicators, such as language, appear (Rothbart, Ahadi & Evans, 2000). Others, however, have argued that how a person reacts to a certain event would be dependent upon the situational context (McAdams & Pals, 2006).

Research has suggested that whilst the traits remain reasonably stable, the expression of them is often contextually dependent. Personality may be potentially inconsistent over time and thus it is not possible for it to be accurately predictable (McAdams & Pals, 2006; Penke, Dennissen & Miller, 2007a, b). Penke et al (2007a, b) argued this point from an evolutionary genetic perspective, which suggest that inherited personality differences explain personality as individual normal genotypic reactions across environments. Further research

has also argued for the importance of considering both stable personality traits while allowing for the measurement of concurrent state-affect components, when measuring affective states (Clark, Vittengl, Kraft & Jarrett, 2003).

1.7.2 Influence of personality traits on adult anxiety and depression

When examining for affective disorders, the main two traits involved are extraversion and neuroticism. Neuroticism at moderate levels predisposes an individual to feel unhappy and have lowered life satisfaction, whereas at higher levels it could predispose the individual to clinical anxiety and /or depression (Trull & McCrae, 2005). The fact that neuroticism is such a significant predictor of affective disorders is perhaps unsurprising as the taxonomic constructs measure neuroticism with descriptors such as fear, anger, anxiety, sadness, guilt and an enduring propensity towards negative emotional states (Goldberg, 1992; Shiner & Caspi, 2003). In contrast, high levels of extraversion are associated with positive emotionality and sociability (McCrae et al. 2000; Watson, Gamez & Simms, 2005) and a decreased use of psychiatric services (Jylhä & Isometsä, 2006). The extraversion dimensional trait is measured by descriptors such as energy levels, sociability, dominance and levels of positive emotional states (Shiner & Caspi, 2003). It has been shown that low levels of extraversion are most strongly linked to anhedonia / depressed affect and social and interpersonal anxiety whereas high levels of neuroticism have an established high associated risk with psychopathology, particularly subjective distress and dysphoria (Watson et al. 2005).

Similarly, other research has also found that the trait most closely associated with anxiety and depression is high levels of neuroticism (Hutchinson & Williams, 2007; Jylhä & Isometsä, 2006; Lönnqvist, Verkasalo, Mäkinen & Henriksson, 2009; Widiger & Anderson, 2003) and that depression can be predicted by high pre-morbid levels of this trait (Scott, Williams, Brittlebank & Ferrier, 1995). Clark et al (2003) argue that general levels of depression can be measured through both stable trait and concurrent state personality measures, but that change in depression levels can only be measured according to changes in state. However, other research has questioned whether high levels of neuroticism and low levels of extraversion and the development of depression are dependent upon a trait or state situation (Lang & Farmer, 2007). The authors argue that the premorbid state of depression has no strong associations with any of the personality traits; which they starkly contrast with

the highly significant association of trait anxiety, measured by neuroticism, and clinical anxiety.

Lönnqvist et al (2009) suggest that neuroticism is a good predictor of affective disorders, particularly once the personality of an individual has stabilized. This is usually the period after young adulthood but it is not entirely definable as everyone matures at different rates. They found that those with high levels neuroticism are more likely to suffer from affective disorders when faced with stressful life events. Clark, Watson & Mineka (1994) found in a non-clinical cohort that high levels of neuroticism increased vulnerability patterns for both anxiety and depression. Hutchinson and Williams (2007) concurred with this finding and suggest that neuroticism is an underlying vulnerability factor in the aetiology of depression symptoms and this was particularly provoked when daily hassles was added as a mediating factor. Hutchinson and Williams, however, also proposed that it might be that individuals high in neuroticism do not actually experience an increased amount of adverse life events as compared to those who are low in neuroticism but merely perceive that they do.

High levels of neuroticism have been associated with anxiety and depression; whereas strong negative associations have been found between high levels of extraversion and anxiety and depression. It should however be noted that the effect size for extraversion was smaller than that of neuroticism (Jylhä &Isometsä, 2006). They likewise found that high levels of neuroticism and low levels of extraversion could explain depression. They added the caveat that their sample, whilst drawn from the general Finnish population, was often older, married and better educated; these are variables that tend to be associated with lower levels of anxiety and depression (Amato & Cheadle, 2005; Gale et al. 2009; Spinhoven et al. 2010). However, Spinhoven and colleagues did stress the importance of the use of neuroticism and also extraversion in clinical use.

Anxiety and depression episodes have also been attributed to a common genetic factor, which causes a vulnerability towards, and inability to cope with, stress (Kendler, Neale, Kessler, Heath & Eaves, 1993). This then has the cyclical effect of individuals with high levels of neuroticism experiencing more recurrent and severe bouts of depression. Findings from the American National Co-morbidity Survey (Kessler et al. 1996) examined the traits of openness, extraversion and neuroticism in order to establish their potential influence on affective disorders. Openness had no associations with the disorders, extraversion had significant, but modest negative associations with both anxiety and

depression, and neuroticism was highly significantly associated with anxiety and depression. Watson et al (2005) argued that this was due to neuroticism being a fundamental part of subjective distress, which is an important component of affective disorders. They suggest aetiological reasons for the association between personality traits and affective disorders as being either that temperament has an effect upon affective disorders, which can then increase the chances of developing and maintaining the disorders. Or, that the development of the affective disorders could affect the personality traits, leaving them more prone to increased levels of neuroticism, either temporarily or permanently. Lastly, they suggest that personality and affective disorders share the same underlying developmental causes, meaning neither is responsible for the onset of the other.

1.7.3 Influence of personality traits on childhood anxiety and depression

High levels of childhood adversity can significantly increase the risk of higher levels of neuroticism and negative affect, and these affects can become established and prevalent throughout the lifetime in both males and females (Rosenman & Rodgers, 2006). In childhood girls are more likely to report higher neuroticism scores and obtain higher scores on anxiety and depression measures, in contrast to boys who score more highly on extraversion (del Barrio, Moreno-Rosset, Lopez-Martinez & Olmedo, 1997).

Shiner and Caspi (2003) forwarded the notion that high levels of the conscientiousness trait of personal control might not be healthy in children as others may not recognise what they need and consequently their needs might not be met. However, they also acknowledged that personal control in terms of anger might have enabled the growing child to regulate negative emotional systems. Shiner and Caspi also suggested that the polar ends of the agreeableness trait could have considerably different affective results. They found a greater propensity for those children with high anti-social tendencies to have high negative emotionality, whereas those with high pro-social tendencies were more likely to benefit from high positive emotionality.

Previous research has found that siblings of individuals with Down's syndrome exhibit higher levels of agreeableness and conscientiousness, proposed to be due to socialisation processes as caregivers to their disabled siblings at an early age, and greater feelings of family solidarity (Cuskelly & Gunn, 2003). In contrast, other research found that

the personality characteristics of an SDI group did not differ from a control group (Lounds-Taylor et al. 2008).The trait of openness tends to measure characteristics such as curiosity, imagination, intellect and the willingness to try new experiences (Shiner & Caspi, 2003). However, overall, openness appears to have fewer associations with either positive or negative emotions (McCrae & Costa, 1991) and also proved to be non-significant in a study of older people with a mean age of 74.9 years (Ready & Robinson, 2008).

A general consensus towards the development of affective disorders is that they are due to a complex interaction between genetic, environmental and developmental factors (Rutter & Silberg, 2002); with the potential of the depression phenotype being expressed in childhood when, amongst other factors, high levels of neuroticism and caretaker instability are present (Jaffee et al. 2002). It has been suggested that personality dimensions should be taken into account in clinical settings if the patient presents with a chronic affective disorder (Jylhä & Isometsä, 2006; Widiger & Anderson, 2003).

It was interesting that few studies investigated parental style as part of the aetiological roots of personality. Parental characteristics or circumstances have a profound effect upon their relationships with children; as a result of this the children might then develop psychological personality characteristics that could interact with genetic influences (Belsky & Barends, 2002; Plomin, 1994). There seems to be consensus that warm and positive emotionality parenting was associated with sensitive and appropriate parenting behaviours; whereas cold and negative emotionality parenting were associated with less proficient parenting styles (Belsky, Crnic & Woodsworth, 1995; Clark, Kochanska & Ready, 2000). It was proposed that aspects of their children's personalities can be reflected through these parenting behaviours (Shiner & Caspi, 2003).

1.8 Different disability types

1.8.1 Different disability types leading to differential effects

Meta-analyses have examined the effects upon siblings of different disability types (Moore et al. 2002; Rossiter & Sharpe, 2001). Disabilities manifest themselves in different ways; potentially in cognitive development, behavioural patterns and social interactions (Orsmond & Seltzer, 2007a) and the extent of these characteristics can result in differing outcomes for the SDI. Research that has focused on the differences between siblings of

individuals with DS and those with ASD (Hodapp & Urbano, 2007; Orsmond & Seltzer, 2007a, b) have generally found more long-term affective problems in siblings of ASD siblings than those with DS, in not only their feelings towards themselves but also increased pessimism about their sibling's future (Orsmond & Seltzer, 2007a). However, due to the limited amount of empirical comparisons between the disability types, it was necessary for further research to try to disentangle unique factors that might help to explain the different propensities of these siblings towards different types of affective disorders.

Individuals with disabilities can often be recognised by particular characteristics that identify their disability type; this may be through a clustering of patterns of scores on traits along these characteristics. Previous research has generally focused on autistic spectrum disorder (ASD) and Down's syndrome (DS) siblings (e.g., Cuskelly & Gunn, 2006; Hastings, 2003a, b, 2007; Hodapp & Urbano, 2007; Meadan, Stoner & Angell, 2010; O'Brien & Bevan, 2011; Orsmond & Seltzer, a, b; Rosner, Hodapp, Fidler, Sagun & Dykens, 2004; Ross & Cuskelly, 2006). When the siblings have been compared, different outcomes for siblings of those with different disability types have been identified, with ASD siblings usually faring considerably less well than DS siblings (Hodapp & Urbano, 2007; Seltzer et al. 2005). Chapter will examine the affective outcomes of ASD and DS siblings and, as a novel aspect, will also compare these outcomes to Prader-Willi syndrome (PWS) siblings.

1.8.2 Characteristics of Down's Syndrome, Autistic Spectrum Disorder and Prader-Willi Syndrome

Typical behavioural traits are associated with specific disability types. Individuals with DS are typically recognised as happy, sociable and affectionate, with a strong stubborn streak and who tend to be happiest when a routine is followed (www.downs-syndrome.org.uk/information/html). They tend to be high in social competency skills perhaps because of their phenotypical nature as noted above; however, they can also be characterised as daydreamers, impulsive and noncompliant (O'Brien & Bevan, 2011). They make also require extra support and encouragement when trying out solitary new skills of a non-sporting nature (Rosner et al. 2004). A potential problem of Down's syndrome individuals is their increased propensity towards early-onset dementia (Sleegers et al. 2006) and it is recommended that this is taken into account when any competency tests are made on adults with DS (Rosner et al. 2004). Evidence for early intervention strategies in individuals with

DS is mixed; however, the most promising results are where the DS individual is encouraged to be an active participant (Nilholm, 1996). Similarly, Sellinger et al (2006) suggest that individuals with disabilities might benefit from being encouraged to participate in activities in which their syndrome's particular behavioural phenotypes make them more likely to excel. For individuals with DS this particularly included visual-spatial and visual strategy activities, such as board games and word puzzles. The authors also cautioned that a decrease in physical activity participation can be problemtic as the DS individual's age as it can be associated with increased weight gain. The research does stress that whilst being aware of the behavioural phenotypes that might make people with specific disabilities particularly favour specific activities, it should still be the individual requirements that are the most important aspect (O'Brien & Bevan, 2011; Rosner et al. 2004). Rosner et al (2004) questioned whether the particular competencies of the specific disability types should be used in intervention programmes or whether these competencies should be left for the individual to purely enjoy. Sellinger et al (2006), however, suggested that it might be advantageous to encourage intervention programmes on the activities that particular disability types most enjoy, on the basis that this could potentially lessen any emotional distress leaving them freer to really benefit from participation.

Similarly to people with DS, individuals diagnosed with ASD often rely upon a closely followed routine but, in contrast to DS individuals, those with ASD tend to have a decreased tendency to be socially interactive in a reciprocal fashion. They can also be characterised by tendencies towards stereotypical, repetitive behaviours, temper tantrums and self-harming. Importantly, there appears to be a rising prevalence in the diagnosed rates of this condition (Orsmond & Seltzer, 2007b; Seltzer, Greenberg, Orsmond & Lounds, 2005). In a literature review of 12 articles, published between 1997 and 2008, into sibling adjustment of ASD individuals (Meadan et al. 2010) it was suggested that the rate of diagnosed ASD is rising by 10 -17 % per year (Centers for Disease Control and Prevention, 2008, as cited in Meadan et al. 2010). Esbensen et al (2010) found that ASD adults had more limited functional abilities, displayed more problem behaviours and had more unmet service needs, yet received less services that the DS age-matched control group. This suggests that the issues found with ASD individuals continue into adulthood. However, the literature review carried out by Meadan and her colleagues (2010) on ASD siblings concluded that there were mixed results in the outcomes of the SDI. While some siblings displayed no ill-effects due to having an ASD sibling and also displayed high levels of social competence and self-concept

other siblings reported increased internalisation feelings and low levels of pro-social behaviour. Therefore, if intervention should be required, this research does again emphasise the need of much further research and to examine each case individually.

In common with DS and ASD individuals, people diagnosed with PWS also have a strong need for routine and, similarly to ASD individuals, they may also have temper tantrums. This is often caused by an insatiable desire for food. Those with PWS, particularly those with the maternal uniparental disomy (UPD) form of PWS, show additional similarities to individuals with ASD, which include poor social interactions, delayed, aberrant or absent language skills, susceptibility to stress, repetitive speech and repetitive, ritualised behaviours (Dimitropoulos & Schultz, 2007; Veltman et al. 2004). Individuals with Prader-Willi tend to be lacking in social competence, whereby they enjoy solitary activities, such as jigsaw puzzles but are likely to resort to tantrum, particularly if faced with being involved in an activity that does not interest them (O'Brien & Bevan, 2011; Rosner et al. 2004). Their behavioural phenotype indicates that their families might be exposed to higher The levels of stress than other disabilities, such as Williams syndrome or DS (Rosner et al. 2004). However, further research does indicate that PWS individuals have a decrease in their maladaptive behaviours as they age (Sellinger et al. 2006), which should help to alleviate a degree of familial stress. It should, however, also be clearly noted though that PWS individuals are usually happy, loveable people (Prader-Willi Syndrome Association of Victoria, 2011).

above syndromes have a wide range of intellectual capacity, ranging from profoundly disabled to normal or above normal functioning; with the exception of DS where there is always a degree of intellectual deficiency (DSM, IV, 2002; Orsmond & Seltzer, 2007a). The evidence does also suggest that whilst it might be that the genetic marker will put a ceiling on the level of ability that individuals with disability may achieve, their interaction with the environment is also a potent factor in their development (O'Brien & Bevan, 2011). However, the aetiology of the syndromes differ, with DS usually having a non-inheritable chromosomal disorder (www.downs-syndrome.org.uk/information/html); unless they are part of the 3-5% that have been affected by an unbalanced translocation of chromosome 21, which could be familial. PWS also have a chromosomal disorder (Dimitropoulos & Schultz, 2007; Veltman et al. 2004) but it is only suspected of being heritable in 2% of cases, whereas genetic factors do appear to be influential in the aetiology of ASD (Orsmond & Seltzer, 2007b) .

1.8.3 The effect of disability diagnoses on siblings

There have been mixed findings regarding the effects of different disability diagnoses upon siblings; research has previously focussed on comparing the different types of disabilities, and the influence that this could have upon the siblings. This comparison could be either with a matched group from the general population or with a different type of disability (Cuskelly & Gunn, 2006; Hastings, 2007; Kaminsky & Dewey, 2001). A study which compared adult DS and ASD siblings found that the DS siblings managed significantly better than the ASD siblings on measures of sibling relationships, health, affective health and contact with their disabled sibling, particularly in the younger years (Hodapp & Urbano, 2007). The authors suggested that this was due to the 'Down syndrome advantage' (Hodapp & Urbano, 2007, p. 1018), whereby the sibling could have perceived benefits through having a DS sibling in comparison to other disability types. This was often through the stereotypical positive sociability characteristics of the DS brother or sister, which also brought around lowered stress levels within the family and better coping strategies in the mother in comparison to other disability types (Hodapp & Urbano, 2007), which has an all-round positive effect.

Other research found no differences between measures of adjustment, including behaviour, competence and self-concept, when they compared siblings of children with DS and a typically developing control group (Cuskelly & Gunn, 2006). Likewise, a further study found no adjustment differences between sibling groups of DS, ASD and mixed aetiology mentally retarded individuals; furthermore, the siblings of DS children were rated as more positively adjusted in comparison to data from a national UK control sample (Hastings, 2007). In contrast, other research suggests that siblings of ASD children often come from less intimate homes and display less pro-social behaviour (Kaminsky & Dewey, 2001). However, the authors also suggest that siblings of both ASD and DS children are admiring of their disabled siblings and reported less fighting and competition than between normally developing siblings. Interestingly, the Kaminsky and Dewey study found that ASD and DS siblings did not report parental favouritism towards the disabled sibling, which is in contrast to other reports (e.g., Howlin, 1988).

However, other research appears to show considerable discrepancies in SDI outcome depending upon the disability diagnosis. Fisman et al (1996) compared siblings of DS,

pervasive developmental disorder (PDD) and a control group as children, and found elevated rates of affective disorders in the PDD group. PDD individuals include those with deficiencies in social communication, with lack of reciprocity, and who have repetitive and ritualistic behaviours (Orsmond & Seltzer, 2007b). However, Pilowsky, Yirmiya, Doppelt, Gross-Tsur and Shalev (2004) found no differences for ASD siblings in the rates of clinically significant anxiety diagnoses in comparison to siblings who have a disabled sibling of unknown aetiology or siblings with a developmental language disorder. Conversely, another study found a substantially larger proportion of siblings of ASD children with significant adjustment problems, predominantly internalising disorders, with 40% reporting scores that placed them on the at-risk or clinical range; this is compared to between 6 – 13% in normal samples (Ross & Cuskelly, 2006). These findings were consistent with those of Gold (1993) who found that siblings of ASD individuals scored significantly higher on depression symptoms, and also Smith and Perry (2005) who found that 36% of children and adolescents with an ASD sibling reported borderline or clinically significant internalising behavioural problems. Further research found that siblings of children with autism were at significantly higher risk of behavioural and emotional adjustment, to the extent that they were at risk of clinical problems, such as depression, when they are older (Lefkowitz, Crawford & Dewey, 2007).

Siblings of ASD children with an intellectual disability have also been found to have more emotional problems than children with only an intellectual disability or a control sample (Petalas et al. 2009). These results were found via maternal reporting and significantly important factors for the increased SDI vulnerability included the increasing age of the child with autism, being younger than the child with autism, the ASD sibling being male and living in social deprivation. These findings specifically indicated that autism was the problem but also considered that it may also be due to phenotypic similarities (Petalas et al. 2009). However, it has also been noted that childhood diagnoses of affective disorders tended to be less stable and therefore childhood prognoses might not be that dependable (Hettema, 2008).

1.9 Rationale of the Present Study

To date there has been little empirical investigation into the long-term effects of disabled individuals upon their adult siblings, indeed, only 23 articles written since 1977 met

the inclusion criteria for a recent review on the adult sibling literature (Davys et al. 2011). The criteria included being over 18, and that intellectual disability in their sibling had been confirmed. The necessity of carrying out research upon the wellbeing of adult siblings of individuals with disabilities is growing as more people with disabilities survive into late adulthood (Hodapp & Urbano, 2007). There is clearly a gap in the research regarding the long-term impact of disability upon siblings of disabled individuals as adults and this gap needs to be filled. The little information that is available does not give a clear picture. On the one hand research suggests adults can benefit from the experiences of having a disabled sibling (Pilowsky et al. 2004); however, these authors did not measure the sibling groups against a normally developing sibling control group. On the other hand, the effects of having a disabled sibling are potentially detrimental (Piven et al. 1990; Rossiter & Sharpe, 2001; Seltzer et al. 2005). Rossiter and Sharpe (2001) propose different affective results at various life-stages. Although a small but significant effect towards affective disorders was identified in adulthood, only two out of the 25 studies were based upon adults and, therefore, it was difficult to draw conclusive results. Previous research when examining SDI as children has also found mixed results on affective outcomes with some reporting a positive impact (Carpenter, 2000; Cuskelly & Gunn, 2006; Pilowsky et al. 2004; Stoneman, 2001) whereas others have reported a more negative impact (Banks et al. 2001; McHale & Gamble, 1989; Ross & Cuskelly, 2006). My study will seek to expand upon previous research and try to establish if having a disabled sibling has an alleviating, neutral or exacerbating effect upon the prevalence of anxiety and depression symptomatology.

In a recent study examining maternal stress levels, it was suggested that heightened levels of stress are not necessarily caused by the child with disabilities per se. Rather, they are caused by an individual reaction to a combination of stressful factors, independent from, but potentially exacerbated by the disabled child, particularly if the child has low cognitive capabilities (Glenn, Cunningham, Poole, Reeves & Weindlings, 2009). My research, therefore, aimed to include and explore other known factors that can exacerbate affective symptomatology and see if they applied to the long-term impact of having a disabled sibling. The different factors include demographic features, adult attachment styles, personality traits and different disability types. The sibling group was compared to a closely matched control group to try to ascertain whether there were any unique factors within the SDI that could help to explain long-term outcomes.

Demographic factors have been renowned for influencing the propensity of anxiety and depression in individuals. Gender seemingly plays a large role in affective disorders with females considerably more likely to suffer than males (Nolen-Hoeksema, 2001; Parker & Hadzi-Pavlovic, 2001). Within the research on disability, it would appear that as children, sisters are more likely to be involved in additional caretaking responsibilities towards their disabled siblings than their brothers (Crnic et al. 1983; Cuskelly et al. 1998; McHale & Gamble, 1989; Rossiter & Sharpe, 2001; Stoneman et al. 1988) and it was proposed that this might be a contributory factor towards female siblings increased tendencies towards anxiety and depression (McHale & Gamble, 1989; Rossiter & Sharpe, 2001). Whilst, to the best of my knowledge, no studies have directly looked at the age of the SDI and tried to establish if they have higher or lower rates of anxiety and depression than someone of a corresponding age in the general public, the ageing process does seem to have an ameliorating effect upon anxiety (Kendler et al. 2004; Spinhoven et al. 2010). It will be interesting to establish if age does play a part in affective symptomatology for the SDI group. Relationship satisfaction is another prominent factor in alleviating affective symptoms (Amato & Cheadle, 2005). I will seek to ascertain if adult SDI who are involved in a romantic relationship enjoy the affective benefits of having a close partner to support them more than the control group. It might be that the SDI group were used to having their needs coming secondary to their disabled siblings and now enjoy the experience of having an elevated position. Research also shows that being at the lower end of the socio-economic scale is also a factor in an increased likelihood of developing anxiety and depression; this appears to be a particular problem for SDI as children as research has shown that individuals with disabilities, and consequently their siblings, tend to be born into, or turn into, disadvantaged families (Olsson & Hwang, 2008). It will be interesting to see if this set of circumstances hold when the SDI reaches adulthood. However, high levels of educational attainment are proposed to have an ameliorating effect upon anxiety and depression (Bjelland et al. 2008; Gale et al. 2009), the long-term impact of education will be examined to try to establish if the long-term effect of education has a positive influence on affectivity in the SDI.

I consider it surprising that more research has not been carried out into the adult attachment style of SDI when the early background of these individuals would potentially have been more stressful than those brought up with a normally functioning sibling. Therefore, it might be expected that there would be a consequent long-term effect on attachment style. The SDI might have witnessed particular stressful occasions, such as

hospitalization or excessive, prolonged and inappropriate behavioural displays from the disabled sibling and the resultant parental concentration on the disabled child, which would necessarily mean diverting that attention from the SDI. It would be interesting to examine how the SDI reacted to this, for example, whether it was subliminally considered as inadequate parenting, which could have resulted in increased propensities to insecure attachment that, in turn, became ingrained and remained throughout adulthood, or if there was a cognitive response to the necessity of the parental behaviour that could override any long-term attachment insecurities.

To the best of my knowledge there has been no empirical research carried out to establish if there is an association between personality traits, having a disabled sibling, and anxiety and depression symptomatology as adults. The relationship between personality traits and affective disorders is a complex one. It might be that personality traits represent a 'latent vulnerability' (Lang & Farmer, 2007, p.59) in the aetiology of depression. Or it might be that an individual is genetically predisposed to affective disorder symptomatology (McCrae et al. 2000). Or those traits could potentially form a comorbid disorder that result in increased levels of anxiety and /or depression (Lang & Farmer, 2007). Having a disabled brother or sister would undoubtedly have had an influence on the sibling without disabilities and it will be interesting to examine if this had a lasting effect on the development of their personality traits as adults.

Speculatively, it could be imagined that high levels of stress due to either acute or chronic health problems in their siblings or behavioural problems that they had to witness, or perhaps increased caretaking of their disabled siblings when children (Moore et al. 2002; Powell & Gallagher, 1993; Turnbull & Turnbull, 1993) could lead to increased levels of neuroticism (Rosenman & Rodgers, 2006). It has been suggested that those with high levels of neuroticism have a decreased ability to manage stress levels and show a higher prevalence towards anxiety and depression (Kendler et al. 1993). The SDI group might have had fewer opportunities for social activities (Seltzer et al. 2009), which could have resulted in lowered perceptions of social support (Stoneman et al. 1988), which could potentially lead to lower levels of extraversion. This was supported through research that proposed that children with disabled siblings reported lower pro-social tendencies (Giallo & Gavidia-Payne, 2006), which could increase levels of negative emotionality (Shiner & Caspi, 2003).

In addition, possibly witnessing negative behavioural actions in their disabled sibling and understanding that often the sibling has little control over their responses or behaviour, and also witnessing outsiders' reactions (Seltzer et al. 2009) might increase levels of openness as they learned to tolerate different perspectives and the conduct or reactions of others. This openness might have helped ameliorate SDI tendencies towards anxiety and depression symptomatology (Shiner & Caspi, 2003). They might experience higher levels of conscientiousness as they learned to respond to their sibling's medical or behavioural routines and consequently learned high levels of personal control (Shiner & Caspi, 2003).

I also think that it will be necessary to establish if particular types of disability have an effect on the grown-up sibling as this may help us to understand if it is the long-term specific welfare needs of the disabled sibling, depending upon disability type that is potentially problematic or if it is the long-term effects of the disability itself that creates an impact. Previous research has indicated that families who have a disabled member are affected in different ways depending upon the type of disability and how the particular disability is manifested. This could have implications for the relationships that individuals maintain with their disabled siblings into adulthood (Hodapp & Urbano, 2007; Orsmond & Seltzer, 2007a) and also the type of clinical intervention that might be most usefully employed if the sibling requires emotional help (Hastings 2003a, b).

Targeted interventions that could promote healthy relationships between the siblings and also stimulate positive emotional well-being are especially important in adult siblings as other forms of family and social support often become less available (Orsmond & Seltzer, 2007b). This is especially salient as it is necessary to ensure sibling health as these individuals will be amongst the first generation of potential caregivers as with increased medical care, disabled individuals are now much more likely to survive into late adulthood (Hodapp & Urbano, 2007). These authors urged future research to gain a greater understanding into the requirements and underlying characteristics of the siblings of both DS and ASD individuals, as they will be the ones who will be increasingly responsible for the life-long welfare of their disabled siblings.

Further, given the steadily increasing occurrence of diagnoses of autism (Seltzer et al. 2005), and the increased prevalence that siblings of ASD have towards affective disorders, (Fisman et al. 1996; Hodapp & Urbano, 2007), the urgent requirement to undertake research into this area is indicated (Orsmond & Seltzer, 2007b; Seltzer et al. 2005), in order that

underlying causes can be established. PWS siblings are a group that are rarely studied and it will be interesting to broaden the research to establish if there are salient characteristics that are specific to PWS individuals that can shed light on the development of sibling affective disorders. There were not enough participants to generate sufficient statistical power for the other disabilities under study. My study, therefore, tried to establish some of the aetiological causes in the reporting of anxiety and depression symptomatology for the disability types of DS, ASD and PWS. This could be especially important if any of the SDI presented for clinical therapy as some of the aetiological causes for affective distress could be specifically addressed. Or perhaps, particular interventions could take place within the particular SDI groups, in order to prevent affective issues regarding the disabled sibling becoming established in the first place.

Research on the topic of the adult affective consequences of having a disabled sibling is, as yet, scarce (Greenberg, Seltzer, Krauss, Chou & Hong, 2004; Hodapp & Urbano, 2007; Krauss, Seltzer, Gordon & Friedman, 1999; Lounds-Taylor, Greenberg, Seltzer, & Floyd, 2008; Orsmond& Seltzer, 2007a,b; Orsmond, Seltzer, Krauss & Hong, 2003; Piven, Gayle, Chase, Fink & Landa, 1990; Seltzer et al. 2005, 2009); consequently much of the work carried out here will be exploratory; it will therefore, be able to form the foundations for future research into this important area. It should also be noted that the SDI data collected for this study was especially valid as it came directly from the participant; this addressed a concern of previous researchers regarding conclusions being drawn about the affective behavioural and emotional adjustment of SDI from maternal reporting (e.g., Hastings 2002, 2003a, b) and the potential for information bias that this could present (Moore et al. 2002).

A unique contribution my research will make will be to examine the effects that attachment styles and personality traits have upon affective outcomes for the SDI and this was in comparison to a closely matched control group. The groups were matched in terms of gender, age and relationship status as primary aims and thereafter matched as closely as possible with socio-economic status. These models might consequently help to explain any affective outcomes that the SDI may present with. Additionally, my research also tried to seek to ascertain if there are differences regarding the long-term affective outcomes of siblings of DS individuals compared to those who have ASD siblings (Hodapp & Urbano, 2007; Orsmond & Seltzer, 2007a,b) and likewise, to those who have siblings with Prader-Willi syndrome (PWS). This is another original contribution to research as PWS siblings

have not previously been compared in this context. The research will help to try to tease out which aspects of the disability might have caused the greatest impact on the siblings.

1.10 Aims of the Present Study

The study examined whether the variables under examination, which included demographic features, perceived parenting styles, attachment styles and personality traits, were influencing anxiety and depression symptomatology. Thereafter, moderation and mediation analyses were calculated to try to understand the significant influences. Moderation analyses would explain if one level of a variable was dependent upon the level of a further variable to have a significant interaction effect on the outcome variable. It has previously been suggested that if a moderation effect was significant then the main order effect should be ignored (Goodwin, 2009; Howell, 2009) because the significant area of interest would then be in the interaction effect, particularly on the one variable that differed from the other three (Goodwin, 2009). However, if the results are significant for both variables, just more definite for one of them, then both main order effects remain of value and should be considered within the analyses (Howell, 2009). These aspects will both be considered.

Given that having a disabled sibling as a single factor is not sufficient reason to cause increased anxiety affective symptomatology, it would appear that other variables are therefore required to explain the route to development of increased symptomatology (Glenn et al. 2009). My study will focus on the potentially intervening variables of perceived parenting styles, attachment styles, personality traits and specific disability types, in order to try to explain anxiety and depression symptomatology. Therefore, in this study, mediation analyses were carried out in order to help explain how the main effect of one variable can be communicated through another main effect to create the outcome (Drotar, 2000).

1.10.1 In response to vast quantities of anecdotal comment, the primary aim of my study was to establish whether there was a significant empirical difference in anxiety and depression symptomatology between adult SDI and a closely matched control group. An increased propensity towards affective symptomatology had been identified in many SDI as children

(e.g., Rossiter & Sharpe, 2001) and an obvious and persuasive question was to ascertain if this remained the case in adulthood.

1.10.2 My second aim was to establish whether there were any demographic variables that might have moderated the relationship between having a disabled sibling and anxiety and /or depression symptomatology. Moderation analysis will allow me to establish whether there are any interaction effects between the demographics and the affective disorders and so I will be able to identify any significant variables that could increase or decrease this association (Holmbeck, 1997). A moderator has been described as 'a variable that affects the direction and / or strength of the relation between a predictor and a criterion variable' (Baron & Kenny, 1986, p. 1174). The demographic variables were chosen on a theoretically driven basis, due to previous research indicating significant relationships between them and anxiety and /or depression (Grant et al. 2006; Nolen-Hoeksema, 2001; Spinhoven et al. 2010; Bjelland et al. 2008).

1.10.3 My third aim was to discern whether there were any factors that were specific to the SDI group, such as severity and prognosis of the disability, parental adjustment to the disability, who presently cares for the disabled sibling and if the disabled individual was born before or after the sibling that would either increase or decrease the association with anxiety and /or depression symptomatology. Again these variables were examined on the suggestion of past research indicating that future studies should investigate them further (Hastings, 2003b; Levy-Wasser & Katz, 2004; Noller, 2005; Rossiter & Sharpe, 2001).

1.10.4 My fourth aim was to establish whether perceived parenting styles, attachment styles and / or personality traits could mediate the relationship between having a disabled sibling and anxiety and /or depression symptomatology. As having a disabled sibling is not a factor in isolation that can cause anxiety and /or depression; there needs to be a catalyst that will exacerbate any tendencies towards increased symptomatology. Mediation analysis will allow me to establish whether attachment or personality could theoretically and statistically explain the association between the predictor and criterion variable (Baron & Kenny, 1986; Frazier, Tix & Barron, 2004; Grant et al. 2006). A mediator can be explained as the factor through

which a predictor variable can influence a criterion variable (Baron & Kenny, 1986). Attachment theory and the Big Five personality theory have been chosen on a theoretically driven basis; to the best of my knowledge they have not been examined specifically with adult SDI. However, there is a wealth of past research that indicates that these may be theories that can help to explain why having a disabled sibling can potentially predict anxiety and /or depression symptoms in this group.

1.10.5 My final aim was based on previous studies (Hodapp & Urbano, 2007; Orsmond & Seltzer, 2007b), whereby the adult siblings of individuals with DS, ASD and PWS were compared. The previous studies were both concerned about the future well-being of the adult siblings and results showed that the siblings of DS individuals had lower levels of depression symptoms (Hodapp & Urbano, 2007); whereas siblings of ASD individuals tended to be more pessimistic about the future of their disabled sibling (Orsmond & Seltzer, 2007a). The novel aspect of my study was that I also tried to ascertain whether there were specific qualities within siblings of PWS individuals that differentiated them from DS, ASD and control siblings The aim of my study was to ascertain whether differences in attachment styles and /or personality traits could explain any differences in anxiety and /or depression symptomatology between the groups. However, due to the sample sizes not being sufficiently large to generate enough statistical power, more in-depth analyses, such as mediation, could not be carried out here.

1.11 Hypothesis testing and research questions for anxiety and depression

Initially, I questioned if there would be a higher prevalence of anxiety and depression symptomatology in adult siblings of disabled individuals? Having a disabled sibling as a child appears to be a contributory factor towards individuals being more vulnerable to developing affective disorders than those without a disabled sibling; it was important to ascertain whether an increased prevalence towards affective disorders is a permanent condition or a transitory effect in childhood when the daily effects of living with a disabled sibling might be at their peak (McHale & Gamble, 1989; Moore et al. 2002; Piven et al. 1990; Rossiter & Sharpe, 2001). I therefore asked:

1.11.1 Is there a higher prevalence of anxiety and depression symptomatology in adult siblings of disabled individuals?

1.12 Hypothesis testing and research questions for demographic features

I then asked whether demographic variables would have an effect on anxiety and depression symptomatology, particularly for the SDI group. The questions on the independent effects of the demographic variables were informed by previous research, however, the potential moderating effects of the relationship between the demographic variables, having a disabled sibling and the affective disorders was a new application to this specific area. The questions I therefore asked were:

1.12.2 Is there an independent effect of gender upon anxiety and depression symptomatology (Nolen-Hoeksema, 2001; Parker & Hadzi-Pavlovic, 2001)?

1.12.2 Does gender moderate the relationship between having a disabled sibling and anxiety and /or depression?

1.12.3 Is there an independent effect of age upon depression symptomatology (Kendler et al. 2004; Spinhoven et al. 2010)?

1.12.4 Does age moderate the relationship between having a disabled sibling and anxiety and /or depression?

1.12.5 Is there an independent effect of relationship satisfaction upon anxiety and /or depression symptomatology (Amato & Cheadle, 2005; Collins, Cooper, Albino & Allard, 2002; Cooper, 2002; Davis et al. 1998)?

1.12.6 Is there a higher rate of parental divorce within the SDI group? And if so, would this be associated with higher anxiety and depression symptomatology (Amato & Cheadle, 2005; Richardson, 2008)?

1.12.7 Does relationship satisfaction moderate the relationship between having a disabled sibling and anxiety and /or depression?

1.12.8 Is there an independent effect of socio-economic status (SES) upon anxiety and depression symptomatology (Anli & Karsli, 2010; Butterworth et al. 2009)?

1.12.9 Does SES would moderate the relationship between having a disabled sibling and anxiety and /or depression?

1.12.10 Is there an independent effect of educational levels upon anxiety and depression symptomatology (Bjelland et al. 2008; Gale et al. 2009)?

1.12.11 Do educational levels would moderate the relationship between having a disabled sibling and anxiety and /or depression?

1.12.12 Do demographic variables that are specific to the SDI have an effect on anxiety and depression symptomatology?

I also questioned whether demographic variables that are only specific to the SDI would have an effect on anxiety and depression symptomatology. I asked these questions due to the inconclusive findings of past research:

1.12.12.1 Does being younger or older than the disabled sibling have an effect upon anxiety and /or depression symptomatology (Breslau, 1982; Brody, Stoneman, Davis & Crapps, 1991; Gold 1993; Levy-Wasser & Katz; 2004; Lawson & Mace, 2010; Lobato, Miller, Barbour, Hall & Pezzullo 1991; Stoneman, Brody, Crapps & Malone, 1991; Turnbull & Turnbull, 1990)?

1.12.12.2 Does the severity of the disability have an effect upon anxiety and /or depression symptomatology (Hastings, 2003; Heller & Kramer, 2009)?

1.12.12.3 Does the severity of prognosis of their disabled sibling have an effect upon anxiety and /or depression symptomatology (Hastings, 2003)?

1.12.12.4 Does where the sibling now resides have an effect upon anxiety and /or depression symptomatology (Eisenberg et al. 1998)?

1.12.12.5 Does the perceived adjustment of their parents to having a disabled child have an effect upon anxiety and /or depression symptomatology (Moore et al. 2002; Rossiter & Sharpe, 2001)?

1.13Hypothesis testing and research questions for perceived parenting styles and attachment styles

These research questions were asked to ascertain if parental care was perceived as being unpredictable due to the extra demands placed upon the parents by the additional requirements of the disabled sibling which could have resulted in the sibling developing a perception of the parent as emotionally or physically unavailable (Hauenstein, 1990). Research has previously indicated that individuals who perceive parental inconsistency have a higher tendency to suffer from anxiety disorders when they are older (Cassidy et al. 2009). I did not expect for there to be significant differences between the groups on warm or cold parenting styles because these styles are more symptomatic of general traits that could be applied to both groups. All the questions comparing the SDI group and the control group regarding perceived parenting and attachment styles are new applications into this area; however, the general implications are informed through previous research. I therefore asked:

1.13.1 Is there an increased tendency for the SDI group to perceive more inconsistent parenting, particularly mothering, than the control group (Hauenstein, 1990; McHale & Gamble, 1989; Moore, Howard & McLaughlin, 2002; Rossiter & Sharpe, 2001)?

1.13.2 Is inconsistent parenting associated with heightened anxiety and depression symptomatology (Cassidy et al. 2009; Wearden et al. 2008)?

1.13.3 Is inconsistent parenting associated with adult attachment-related anxiety (Cassidy et al. 2009; Wearden et al. 2008)?

1.13.4 Do perceived inconsistent mothering and /or inconsistent fathering mediate the relationship between the increased reporting of anxiety and /or depression symptomatology within the SDI group?

I also wanted to ascertain if there was a difference in adult attachment styles between the SDI and control group. This is related to the last research questions whereby it was questioned if the SDI might have perceived a higher rate of inconsistent parenting and if this would follow through to increased levels of attachment-related anxiety (Rholes et al. 1998). Perceived parental unavailability or overprotection, through a fear that anything should happen to their 'well'-child (Heinonen et al. 2004; Hinnen et al. 2009; Kaitz & Maytal, 2005), could also lead to attachment-related anxiety as an adult (Ainsworth et al. 1978). Attachment-related anxiety might be maintained as an adult if the disabled sibling has medical problems, which leave them at constant risk of hospitalization, severe medical illnesses and / or severe behavioural incidents (McHale & Gamble, 1989) or if there is a perceived shift in responsibility for the disabled sibling from parent to sibling (Hodapp & Urbano, 2007). Consequently, if the SDI is in a state of constant hyper-vigilance in order to assure the well-being of the brother or sister, this could again maintain symptoms of attachment-related anxiety in the SDI (Mikulincer & Shaver, 2007; Simpson & Belsky, 2008). I therefore asked:

1.13.5 Is there a difference in adult attachment styles between the SDI and control group?

1.13.6 Does attachment-related anxiety mediate the relationship between the increased reporting of anxiety and depression symptomatology within the SDI group?

1.14 Hypothesis testing and research questions for personality traits

I also questioned whether there would be an increased tendency for the SDI group to report higher levels of neuroticism (Moore et al. 2002; Powell & Gallagher, 1993; Rosenman & Rodgers, 2006; Turnbull & Turnbull, 1993) and openness (Seltzer et al. 2009) and lower levels of extraversion (Stoneman et al. 1988) than the control group. This was due to potentially higher levels of stress or hassles (Hutchinson & Williams, 2007) relating to the disability that the SDI encountered when younger and to establish whether the pattern of responses had been maintained into adulthood. Neuroticism is the trait most closely associated with anxiety and depression (Hutchinson & Williams, 2007; Trull & McCrae, 2005; Watson et al. 2005) and, similarly, previous research has also found that low levels of

extraversion are robust and consistent markers of depressed affect and social/interpersonal anxiety (Jylhä & Isometsä, 2006; Watson et al. 2005). However, the effect for extraversion upon anxiety and depression tends not to be as strong as with neuroticism (Jylhä & Isometsä, 2006). Thereafter, openness was examined because the SDI probably experienced, and had to deal with, unusual life events regarding their disabled sibling when growing up, which might have created higher openness levels A link between openness, anxiety and depression has not yet been established, with the majority of research finding little association between the variables (Kessler et al. 1996; McCrae & Costa, 1991; Ready & Robinson, 2008; Watson et al. 2005). It also wanted to examine if the agreeableness and conscientiousness traits would be higher in the SDI group than the control group, possibly due to the caregiving towards their disabled sibling that they gave in the early years (Cuskelly & Gunn, 2006). All the questions comparing the SDI group and the control group regarding personality traits are new applications into this area; however, the general implications are informed through previous research. I therefore asked:

1.14.1 Is there a difference between levels of extraversion, neuroticism, openness, agreeableness and conscientiousness between the SDI and the control group?

1.14.2 Does extraversion mediate the relationship between the SDI and anxiety and /or depression symptomatology?

1.14.3 Does neuroticism mediate the relationship between the SDI and anxiety and /or depression symptomatology?

1.14.4 Does openness mediate the relationship between the SDI and anxiety and /or depression symptomatology?

Childhood events can have a significant influence upon the life-course (Cassidy et al. 2009; Moore et al. 2002; Rosenman & Rodgers, 2006; Rossiter & Sharpe, 2001; Wearden et al. 2008) and it would be interesting to establish the significance of the perceived parenting in relation to the adult personality variables of neuroticism, extraversion and openness (Belsky & Barends, 2002; Plomin, 1994; Shiner & Caspi, 2003). I therefore asked:

1.14.5 Is there an association between perceived inconsistent parenting and the adult personality variables of neuroticism, extraversion and openness (Belsky & Barends, 2002; Plomin, 1994; Shiner & Caspi, 2003)?

1.15 Hypothesis testing and research questions based on disability types

Previous research has indicated that ASD siblings have an increased tendency towards anxiety and depression symptomatology (Gold, 1993; Ross & Cuskelly, 2006; Smith & Perry, 2005) in comparison to those whose siblings have DS and control groups (Hastings, 2003, a, b; Lefkowitz et al. 2007). However, lack of previous research makes it was difficult to know the long-term affective reactions of those with PWS siblings. Recent literature does suggest that PWS individuals can display phenotypical maladaptive behavioural tendencies (O'Brien & Bevan, 2011; Rosner et al. 2004), which can create additional lifelong stress for their families (Rosner et al. 2004); despite other research indicating the behaviours weaken as the PWS individuals age (Sellinger et al. 2006). However, on balance it will be interesting to ascertain if siblings of PWS affective symptoms are higher than the control group and the DS group (Fisman et al. 1996) and how they compare to the ASD group. Also questioned will be if there is a significant difference between the groups and the DS siblings. Previous research has suggested that DS siblings do particularly well, possibly due to the proposed 'Down syndrome advantage' (Hodapp & Urbano, 2007). I therefore asked:

1.15.1 Do ASD siblings have an increased tendency towards anxiety and depression symptomatology in comparison to those whose siblings have DS or PWS (Gold, 1993; Ross & Cuskelly, 2006; Smith & Perry, 2005)?

1.15.**2** Do ASD, DS or PWS groups score higher on these affective disorders in comparison to the control group (Hastings, 2003, a, b; Lefkowitz et al. 2007)?

With the different behavioural phenotypes displayed by the disability groups, and with ASD and PWS individuals potentially displaying more maladaptive traits

(Dimitropoulos & Schultz, 2007; O'Brien & Bevan, 2011; Orsmond & Seltzer, 2007b, Rosner et al., 2004; Seltzer et al., 2005; Veltman et al. 2004) than the DS and control group, I also wanted to ascertain if any of the established measures of perceived parenting (Cassidy et al. 2009; Wearden et al. 2008), attachment styles (Mikulincer & Shaver, 2007; Reis & Grenyer, 2004; Warren et al. 1997) or personality traits (Hutchinson & Williams, 2007; Jylhä & Isometsä, 2006; Lönnqvist et al. 2009; Watson et al. 2005; Widiger & Anderson, 2003) would have any specific association with e sibling disability types. Also, if there would then be any specific association with anxiety and /or depression symptomatology for all the groups under study but particularly so for the ASD and the PWS siblings (Hutchinson & Williams, 2007; Jylhä & Isometsä, 2006; Lönnqvist et al. 2009; Widiger & Anderson, 2003). The reasons for this relates to the varying degrees of behavioural difficulties displayed due to the disability and the consequent affect that it has on the sibling. The questions are novel and I therefore asked:

1.15.3 Is there an association between perceived inconsistent parenting and those with DS, ASD or PWS siblings and their control groups?

1.15.4 Is attachment-related anxiety associated with anxiety and /or depression symptomatology for all the individual groups under study?

1.15.5 Is extraversion associated with anxiety and /or depression symptomatology for all the individual groups under study?

1.15.6 Is neuroticism associated with anxiety and / or depression symptomatology for all the individual groups under study?

1.16 Hypothesis testing and research questions based on birth order

There have been conflicting views over the importance of birth order towards the psychological well-being of SDI, and whether it was more beneficial to be older than the sibling with problems (Friedlin & Florian, 1996; Hastings, 2003; Hauenstein, 1990) or younger (Boyce & Barnett, 1993). The following question only examined the SDI group.

1.16.1 Is there a difference between the attachment styles of siblings who were older or younger than the disabled individual?

1.16.2 Is there a difference between the personality traits of those who were older or younger than the disabled individual?

1.16.3 Do younger siblings with DS, ASD and PWS siblings report higher anxiety and /or depression symptomatology than older siblings?

Chapter 2

Methodology

2.1. Pilot study

2.1.1. Introduction to the pilot-study

Prior to the beginning of the main study, a pilot study was carried out. This was to establish if there were any errors within the questionnaire (see Appendix A) and to ascertain if the established measures that were to be used (see this Chapter, paragraph 2.3) had high internal validity and low levels of inter-correlation. The pilot-study participants were also asked to choose between three anxiety /depression measures, for ease of understanding, scoring and relevance. I also wanted to ascertain if I was gathering sufficient information for the demographic background in order to gain a complete picture, or if any of the participants had trouble understanding any of the questions so that they could then be amended.

2.1.2. Participants of the pilot-study

The 11 participants who were chosen for the pre-test did not have siblings with disability because this was not necessary due to it being a study purely to ascertain that the measures were appropriate. They were also chosen specifically for their wide range of backgrounds and age range. There were 5 males and 6 females and the age range was from 20 to 71. Two of the participants were single, 3 married or cohabiting and 6 were divorced or separated. They were, however, all white and of British origin. The participants were all issued with a consent form that conformed to BPS ethical guidelines. Due to this being a small study it was verbally explained to the participants that full anonymity could not be guaranteed, this was agreed prior to their taking part in the research.

2.1.3. Measures used in the pilot-study

The measures were all chosen on a theoretically driven premise, whereby previous research has shown that the theories are known to have strong associations with affective disorders. They should link equally well to the SDI group and the control group. The

measures used also have proven high reliability with test-retest co-efficients from previous research.

Demographic Information: The questions asked on demographic information were retained for the main study (see Table 3.1); these variables included gender, age, relationship satisfaction, socio-economic status and educational attainment.

The established measures tested were as follows:

Parental Caregiving Style: An adapted measure of Descriptions of Parental Caregiving Style (DPCS: Hazen & Shaver, 1986, unpublished manuscript in Collins & Read, 1990) was also used. This collated attachment measure ascertains how the participants perceived the parenting they received from both mother and father. They were asked to give a single score from 1 – 7 for each of the warm, cold and inconsistent styles for both mothers and fathers.

Attachment Style: The Experiences in Close Relationships scale (ECR: Brennan et al. 1998) was used. This is a 36-point scale, which can assess position on Anxious or Avoidant attachment dimensions, which can be further sub-divided into the attachment categories of Secure, Fearful, Preoccupied or Dismissive.

Personality Traits: The International Personality Item Pool Big Five Markers Scale (IPIP: Goldberg, 1999; http://ipip.ori.org/newBig Five5broadkey.htm , 2001) is a 50-point scale, which is freely available in the public-domain. It assesses the position of the participants on the personality traits of Extraversion, Agreeableness, Conscientiousness, Neuroticism and Openness to Experience. This was compared to the Mini IPIP Scales (Donnellan, Oswald, Baird & Lucas, 2006), a 20-point item scale, based on extractions from the 50-point scale. This is also freely available in the public-domain.

Self-Esteem: Thereafter, the Rosenberg Self-Esteem Scale (RSES: Rosenberg, 1965) was completed. This is a 10-item 4 point scale self-report, which measures global self-esteem. This is one of the most widely used measures to assess self-esteem and it has correlation coefficients of .86 to .90, with test – retest coefficients of .85 (over two weeks).

Social Support: The Multidimensional Scale of Perceived Social Support (MSPSS: Zimet, Dahlem, Zimet & Farley, 1988) was also administered. This is a 12-item, 7 point scale,

whereby 4 items are designed to measure apparent support from friends, family and significant other. The alpha coefficients ranged from .85 to .91 and the test – retest ranged from .72 to .85.

Coping Style: An abbreviated 15 item version of the Cybernetic Coping Scale (CCS) was used (Guppy, Edwards, Brough, Peters-Bean, Sale & Short, 2004). This had Cronbach alpha coefficients of between 0.69 and 0.81; however 3 items were added 'I talk to someone to find out more about the situation', 'I ask a relative or friend I respect for advice' and 'I talk to someone about how I was feeling', as it was felt including social support increased overall reliability of the measure (Guppy et al. 2004).

Locus of Control: The Locus of Control Scale (LCS: Rotter, 1966) was used. This is a one dimensional concept that measures externality to internality. It has received Cronbach's alpha coefficients of 0.71 and test – retest reliability of 0.83 (Gencoz & Astan, 2006).

Anxiety and Depression: The pilot-study participants were asked to compare the following three scales in terms of how easy the questions were to understand, how easy to complete and how relevant the questions were:

1) Center for Epidemiological Studies Depression Scale (CES-D: Radloff, 1977). This is a 20-point, self-report scale, which is freely available in the public domain. It assesses depression symptomatology during the previous week, with scores of 16-26 indicating mild depression and scores of above 27 indicating more severe depression symptomatology.

2) Or 2) Hospital Anxiety and Depression Scale (HADS: Zigmond & Snaith, 1983). This is a 14-point, self-report scale. It assesses both depression and anxious symptomatology, with scores on each scale from 0 -7 within the normal range, 8 – 10 indicating borderline clinical need and those scoring above 11 indicating clinical need. Its use has been validated in community settings (Snaith, 2003).

3) Or 3) General Health Questionnaire (GHQ: Goldberg & Blackwell, 1970). This is a 12-point, self-report scale. It assesses depression symptomatology, with scores above 15 indicating signs of distress. It can be used in a non-clinical setting.

It must be noted that in all analyses it was the self-reported affective symptom scores that were examined and there was no medical assessment made.

2.1.4. Procedure for the pilot-study

The participants read the consent form and then privately completed as much of the questionnaire as they felt comfortable with. The questionnaires were then returned to the Psychology Department at the University of Chester. Thereafter, the individual measures were separately recorded on SPSS v 14 datasheets, the final scores to then be collated on a separate SPSS datasheet. In the demographic information, marital status was recoded for ease of recording; married and co-habiting were collapsed into one group as was divorced and separated but single and widow/er were left alone. The occupation and income section were classified according to social economic status and religion further assumed a numerical value. The completion of the data included reverse scoring for the appropriate questions. The Emotional Stability facet of both the IPIP and the mini IPIP scales were completely reverse coded according to instruction, in order to obtain the Neuroticism facet. The 20 items that constituted the mini IPIP were extracted from the 50 item IPIP scale in order for analysis to be carried out.

2.1.5. Design and analysis of the pilot-study

This was a cross-sectional study design, completed by self-report. Cronbach's alpha was obtained for the majority of the measures. SPSS v 14 calculated the descriptives and the inferential statistics used were correlational analysis. The DVs were the anxiety and depression variables and the IVs came from the established measures used. The alpha level was set at $p \leq .05$.

2.1.6. Results for the pilot-study

Descriptive statistics

Please see Appendix B for the tables displaying the descriptive statistics for all the measures. The descriptive statistics showed that the reliability for symptom reduction item of the CCS was low, however, if item 13 is deleted, the alpha level is raised to .67. When the reliability for the mini IPIP was computed the alpha levels were consistently lower than for the full IPIP. However, when item 2 is deleted on the Extraversion scale the alpha level rises to .84; when item 9 on the Neuroticism scale is omitted the alpha level rises to .71; when item 17 is deleted on the Agreeableness scale the alpha level rises to .59 and likewise if item 18 is deleted on the Conscientiousness scale the alpha level rises to .81. However, given that the Mini IPIP is only a 20 point scale, it was felt that having to delete items leaving only 3 items to score personality factors would not be sufficiently accurate or reliable, and thus the Mini IPIP was excluded from further analysis. The descriptive statistics further showed that participants reported high levels of IPIP Agreeableness but low levels of Neuroticism. The results also showed higher levels of anxious rather than avoidant attachment styles. However, when broken down into categories it was found that 64% were securely attached, 9% fearfully attached, 9% preoccupied in their attachment style and 18% were dismissively attached.

Support seeking was the most popular style of coping, but all forms of coping were within the normal range. Friends were used as the highest source of social support, followed by family and then significant other. The significant other being the least used form of social support might be explained by only 3 out of the 11 participants being married or co-habiting. Overall, the participants appeared to report reasonably high levels of self-esteem. There was a very slight trend towards an internal locus of control. Low mean scores were recorded for all the affective measures; however, the HADS did show a much higher mean scoring for anxiety rather than depression.

Inferential statistics

Correlational analysis revealed an expected association between the IPIP's Neuroticism and both avoidant attachment ($r = .63$, $p = .04$) and anxious attachment ($r = .64$, $p = .03$). It further showed that high levels of Neuroticism were inversely associated with self-esteem (r

= -.61, p = .05). IPIP's Conscientiousness was related to perceived social support (r = .70, p = .02), whereby the subscales indicated the relationship with Conscientiousness was broken down into perceived family support (r = .79, p = .004) and perceived support from friends (r = .61, p = .04).

IPIP showed Conscientiousness was further related to the coping subscale of support seeking (r = .67, p = .02). Likewise, the Openness to Experience was inversely related to the coping subscale of accommodating (p = -.72, p = .01). However, the accommodating coping subscale showed a positive relationship with self- esteem (r = .72, p = .01).

When the measures were compared to the HADS it was shown that avoidant attachment was significantly related to the HADS subscale of anxiety disorders (r = .65, p = .03). There were trends between anxious attachment and the anxiety subscale (p = .07) and also the depression subscale (p = .07), but neither reached significance. There were also significant associations between Neuroticism and the anxiety subscale (r = .71, p = .01). An inverse relationship was also shown between self-esteem and the anxiety subscale (r = -.75, p = .008).

Correlational analysis for the HADS, GHQ and CES-D depression scales showed that when HADS was broken down into its subscales (anxiety and depression) GHQ and CES-D only correlated with the anxiety subscale (r = .65, p = .03; r = .77, p = .005, respectively). However, GHQ and CES-D did show a high association (r = .88, p < .001). Whereas, CES-D was not quite so strongly associated with HADS (r = .77, p = .006), and GHQ showed an even less significant relationship to HADS (r = .65, p = .03).

Further, neither the GHQ nor the CES-D showed much inter-relation with the other measures. The only associations to be found for the GHQ were with avoidant attachment (r = .69, p = .02) and anxious attachment (r = .68, p = .02). CES-D was only related to avoidant attachment (r = .61, p = .05), and it was inversely related to both self-esteem (r = -.63, p = .04) and the accommodating subscale of the coping inventory (r = .62, p = .04).

2.1.7. Discussion for the pilot-study

Correlational analysis revealed a significant amount of interrelationships between the measures, with the exception that no relationship was found between any of the measures and Rotter's Locus of Control scale. However, before analysis had begun on the main study it

was decided to omit the scorings from the Locus of Control Scale, Cybernetic Coping Scale, the Multi-dimensional Scale of Perceived Social Support and the Rosenberg Self-Esteem Scale from the analyses for the thesis. This was because it was felt that a more in-depth, meaningful set of analyses could take place with the remaining measures, which are Descriptions of Perceived Parental Caregiving, Experiences in Close Relationships, International Personality Item Pool and the Hospital Anxiety and Depression Scale. These variables were chosen to be included in the analyses because they tend to be deeper, more intransigent variables that can perhaps give a fundamental understanding as to the development and maintenance of any affective disorders. The other variables that will hopefully be examined in future research include self-esteem, coping strategies, perceived social support and locus of control; these can be viewed as more of surface traits that can be more flexible depending upon current circumstances, especially interpersonal events (Aspendorf & van Aken, 2003). Further, the participant scoring on the surface trait variables may be based on their scores from the 'deeper' measures as they can intrinsically affect reactions to different situations. These variables, when they come to be examined, will hopefully give a much broader understanding as to why affective disorders can be developed and maintained in certain individuals. In the meantime, an in-depth study can initially be carried out to ascertain if there are any differences between the disabled sibling and control groups and anxiety and depression symptomatology, and then to establish if the relationship could be mediated through perceived parenting styles, attachment styles or personality traits.

It was known that the SDI group was going to be very closely matched to a control group, in terms of gender, age, relationship status and socio-economic status. It was fully recognised that this would be a difficult and time consuming process and so the scales of self-esteem, coping strategies, perceived social support and locus of control were still included within the questionnaire so that further analyses can take place once this present study has been completed.

Due to the low coefficients of the Mini IPIP it was decided to use the lengthier 50 item IPIP scale, whilst this may not be so user-friendly in terms of the amount of time needed to complete it, the alpha scorings were all of high acceptability. The small sample size has to be taken into account for this result; however, the main focus of this research will be on the Neuroticism facet for which no problems were found.

When the participants were asked for a preference out of the 3 depression scales, based on how easy to understand, how easy to complete and how relevant they were perceived as being, out of the 11 participants who took part in the pilot study 6 preferred the HADS questionnaire, 2 the CES-D and the 3 remaining participants did not state a choice. The HADS scale was chosen to be the affective disorder scale in the main research due to this preference and also on account of the way it differentiated anxiety from depression. It can be seen from the results that neither the GHQ nor the CES-D showed any relation with either the IPIP or mini IPIP Neuroticism facet; this is in contrast to HADS where both the measures showed high levels of Neuroticism were significantly correlated towards both overall affective disorders and in particular anxiety, which is in line with current theory (Watson , Gamez & Simms, 2005). Research has proposed that Neuroticism can act as either a moderator or a mediator in the development of depression (Clarke, 2004) and there are also clearly established links between Neuroticism and anxiety (Shiner & Caspi, 2003). It appeared from the pilot-study that HADS had a higher propensity to tap into this element than the other two measures.

Interestingly, both GHQ and CES-D only correlated with the anxiety subscale of HADS and not the depression subscale. Whilst there is often a high degree of co-morbidity between anxiety and depression, they are in fact separate constructs with differing psychological and physiological symptoms (Parker & Hadzi-Pavlovic, 2001) and it is also proposed that they have differing developmental causes. Consequently it was deemed that the HADS, with its clear clinical distinction was the best measure to use. However, it must be remembered that the results found within the pilot-study may be due to the small sample size. This was indeed a limitation of the pilot-study in that no further in-depth analysis could be undertaken.

2.1.8. Conclusions for the pilot-study

The questionnaire overall was considered valid. The 50-item-IPIP scale was chosen over the 20-item IPIP scale, due to the low alpha scorings of the shorter scale. HADS was chosen to be used as the affective measure as it appeared to produce the most reliable and in-depth results. It was decided to omit a number of measures from the main study analyses; however, these measures were still included in the main study's questionnaire so that analyses could potentially be carried out at a later stage. It was decided to focus on the

variables of perceived parenting styles, attachment styles, personality traits and also add the different disability types of siblings as an additional variable.

2.2. Main study

2.2.1. Participants

Participants with a disabled sibling

The participants were selected on the basis of being non-disabled siblings of disabled individuals and they constituted 150 individuals who responded to a postal questionnaire (see Appendix C). The participants were selected through several disability charities, which included SIBS, the Down's Syndrome Association, the National Autistic Society and the Prader-Willi Society. The criterion for inclusion in the study was that participants were over 18 years of age. Children tend to go through pronounced developmental stages according to their age and consequently should be measured stage by stage. However, in this study, the age range was 19-71 years, so whilst acknowledging there is still a lot of scope for changes in the age groups over this period, potential of skewed data should be somewhat lessened due to the less dramatic different developmental stages that adults display as variations in characteristics within the individual tend to be smaller as people age. Further, by studying the long-term effects on the adult sibling I excluded the fluctuations of normative childhood experiences of sibling relationships from early childhood through to adulthood (Cicirelli, 1995). When individuals are aged 18+, they are usually less dependent upon the nucleus family, this independence will often assume less daily contact with the disabled sibling and so it is then possible to begin to tease out if the increased prevalence towards affective disorders is a long-term issue or a more of a transient effect in childhood when contact with the disabled sibling might be at its highest (McHale & Gamble, 1989; Moore et al. 2002; Rossiter & Sharpe, 2001). The demographics for the SDI are listed in Tables 3.1 and 3.2.

Control group participants

A further 150 participants were selected for the control group. These participants were found through friends, families, colleagues and some requests were made to hairdressers and local shops in order to match participants. They were as closely matched to the SDI group as possible on the basis of gender, age, marital status and, where possible, socio-economic status. This was achieved through matching each participant with a disabled sibling with one

from the control group; gender was always applied, age was invariably applied to within 10 years (younger participants were invariably matched to within 2 years), marital status was applied in the majority of cases and socio-economic status was applied to within 1 point on either employment status or annual income but usually on both. This was done in order to ensure that like was being matched with like and consequently the results would not be skewed by comparing unequal groups. The study was carried out in accordance with BPS ethical guidelines and passed by the University of Chester's ethical committee (see Appendix D). The demographics for the control group are shown alongside the data for the SDI group in Table 2.1. McNemar test of proportions was used to ascertain if there were any significant differences between the groups (http://graphpad.com/quickcalcs/McNemar2.cfm).

Table 2.1: Demographic variables for SDI and control groups

	SDI (N =150)	Control (N=150)	McNemar (Chi-sq) test result
Gender (N = 300)			
Male	33	33	
Female	117	117	χ^2 (1) = 0.00, p = 0.95
Age groups (N = 296)			
19 – 23	21	20	χ^2 (1) = 0.00, p = 1.00
24 – 29	34	24	χ^2 (1) = 1.40, p = 0.24
30 – 39	52	39	χ^2 (1) = 1.58, p = 0.21
40 – 65	41	58	χ^2 (1) = 2.51, p = 0.11
65+	1	4	χ^2 (1) = 0.80, p = 0.37
(Missing)	1	5	
Marital status (N = 300)			
Single	50	40	χ^2 (1) = 0.90, p = 0.34
Married /co-habiting	92	91	χ^2 (1) = 0.00, p = 1.00
Divorced /separated	7	17	χ^2 (1) = 3.38, p = 0.07
Widow /er	0	2	χ^2 (1) = 0.50, p = 0.48
Relationship satisfaction (N = 225)			
Extremely unsatisfactory	3	2	χ^2 (1) = 0.00, p = 1.00
Unsatisfactory	6	5	χ^2 (1) = 0.00, p = 1.00
Satisfactory	26	36	χ^2 (1) = 1.31, p = 0.25

Extremely satisfactory	76	71	χ^2 (1) = 0.11, p = 0.74
(Missing)	39	36	
Annual income (N = 258)			
Under £10,000	27	26	χ^2 (1) = 0.00, p = 1.00
£10,001 -£15,000	11	30	χ^2 (1) = 7.90, p = 0.01
£15,001 -£20,000	18	21	χ^2 (1) = 0.10, p = 0.75
£20,001 -£30,000	35	24	χ^2 (1) = 1.70, p = 0.19
£30,001 -£45,000	23	18	χ^2 (1) = 0.39, p = 0.53
£45,001 -£70,000	9	9	χ^2 (1) = 0.00, p = 1.00
£70,001+	8	9	χ^2 (1) = 0.00, p = 1.00
(Missing)	19	13	
Socio-economic status (N = 277)			
Higher managerial (1)	8	5	χ^2 (1) = 0.31, p = 0.58
Lower managerial (2)	29	24	χ^2 (1) = 0.30, p = 0.58
Intermediate occupations (3)	24	20	χ^2 (1) = 0.21, p = 0.65
Small employer /self-employed (4)	10	12	χ^2 (1) = 0.05, p = 0.83
Lower supervisory /technical (5)	22	18	χ^2 (1) = 0.23, p = 0.64
Semi-routine (6)	21	27	χ^2 (1) = 0.52, p = 0.47
Routine (7)	3	5	χ^2 (1) = 0.13, p = 0.72
Students, retired, etc (0)	23	26	χ^2 (1) = 0.08, p = 0.78
(Missing)	10	13	
Educational Qualifications (N = 294)			
Postgraduate	31	20	χ^2 (1) = 1.96, p = 0.16
Degree	66	36	χ^2 (1) = 8.25, p < 0.01
‘A’ levels	24	35	χ^2 (1) = 1.70, p = 0.19
GCSE (equivalent)	22	41	χ^2 (1) = 5.14, p = 0.02
Technical	2	3	χ^2 (1) = 0.00, p = 1.00
None	4	11	χ^2 (1) = 2.40, p = 0.12
(Missing)	1	4	

Table 2.1 shows that the only significant differences between the groups was that more control participants had an annual income of between £10,001 - £15,001 and that more SDI participants reported a higher level end qualification than the control group. There was a non-significant trend for the control group to report divorce or separation than the SDI group.

Table 2.2 shows the demographic variables specific to the SDI group (N= 150). The frequencies are also included for clarity (Heller & Kramer, 2009; Esbensen et al. 2010).

Table 2.2: Variables exclusive to the total SDI group

Variables	N	%
Maternal adjustment		
Extremely well	43	29
Very well	32	21
Quite well	37	25
Quite poorly	10	7
Very poorly	17	11
Extremely poorly	8	5
(Missing)	3	2
Paternal adjustment		
Extremely well	36	24
Very well	33	22
Quite well	29	19
Quite poorly	18	12
Very poorly	13	9
Extremely poorly	15	10
(Missing)	6	4
Age group of disabled sibling		
19 – 23	25	16
24 – 29	41	27
30 – 39	52	35
40 – 65	30	20
65+	1	1

(Missing)	1	1
Diagnosis of disability		
Undiagnosed	16	11
Down's syndrome	6	4
Epilepsy	6	4
Rare	7	5
Viral	2	1
Prader-Willi syndrome	26	17
Fragile X syndrome	3	2
Autistic spectrum disorder	33	22
Severity of disability		
Mild	10	6
Moderate	58	39
Severe	58	39
Profound	21	14
(Missing)	3	2
Prognosis		
Better	2	1
Same	19	13
Worse	10	7
Death	14	9
No prognosis	48	32
(Missing)	57	38
Living with disabled sibling		
Yes	13	9
No	136	90
(Missing)	1	1
Primary carer		
Yes	3	2
No	146	97
(Missing)	1	1

Table 2.2 shows that the majority of mothers and fathers were reported to have adjusted well to coping with the disability, that the majority of siblings who responded were within the 30 – 39 age bracket, that most respondents classed their sibling disability within the moderate to severe categories and that only two out of the 150 participants expected their sibling to get better. The vast majority of the siblings were not living with their disabled sibling and only three out of the 150 SDI participants were classed as their sibling's primary carer. The most common disabilities noted were DS, ASD and PWS and consequently it was these three disabilities that were examined in depth when trying to ascertain differences in sibling responses between disability types.

Participants for the individual disability groups

The groups of participants for this study were extracted from the main cohort. The groups were chosen on the basis of having a sibling whose disability was ASD, DS or PWS; the control group for each of the subsets was made up from the participant that the SDI was matched with in the initial analyses. This data was found by looking at the separate spread-sheets for the SDI and control groups and if, for example, a DS sibling's data had been input under number five, it would be copied and transferred to a newly created spread-sheet. The participant numbered five from the control group's spread-sheet would also then be copied and transferred to the new spread-sheet.

Initially the demographic variables of the DS group, the ASD group and the PWS group were examined to ascertain if there were any group differences. Table 2.3 shows descriptive information on the demographic characteristics of the 120 participants between the three different disability types. When I was gathering the data for the different disability type group, the only additional action was to manually go through the data files and copy the siblings and their matched controls to newly created data files for the ASD group, the DS group, the PWS group and their specific control groups. I also then recoded them into disability type for the One-way ANOVA analysis with DS being coded as 1, ASD as 2, PWS as 3 and the control group as 4.

Table 2.3: Frequency data for Down's syndrome, autistic spectrum disorder and Prader-Willi syndrome demographics with differences between groups analysed through One-way ANOVAs using mean values

	DS (N=61)	ASD(N=33)	PWS (N= 26)	One-way ANOVA
Gender				
Male	20	3	8	
Female	41	30	18	
(frequency levels –female %)	66.7	90.6	69.2	F (2,117) = 2.13, p = 0.12*
Age groups				
19 – 23	2	9	6	
24 – 29	19	6	9	
30 – 39	27	10	5	
40 – 65	13	8	6	
65+	0	0	0	
(Missing)	0	0	0	
(mean/ SD levels)	33.30 (8.95)	32.36 (11.15)	30.65 (9.70)	F (2,117) = 3.46, p = 0.04**
Relationship satisfaction				
Extremely unsatisfactory	2	0	0	
Unsatisfactory	4	0	1	
Satisfactory	9	11	2	
Extremely satisfactory	35	25	14	
(Missing)	11	8	9	
(mean /SD levels)	3.55 (0.82)	3.54 (0.51)	3.37(1.30)	F (2,91) = 0.32, p = 0.73
Age relation to disabled sibling				
Younger	27	12	12	
Older	34	20	14	
Missing	0	1	0	
(frequency – older %)	56.7	61.3	53.8	F (2,116) = 0.26, p = 0.77
Maternal adjustment				
Extremely poorly	5	3	0	
Very poorly	2	6	1	
Quite poorly	2	2	0	

Quite well	10	9	10	
Very well	15	4	7	
Extremely well	26	7	8	
(Missing)	1	2	0	
(mean /SD levels)	4.81 (1.50)	3.84 (1.68)	4.81 (1.02)	F (2,115) = 5.73, p = 0.004***
Paternal adjustment				
Extremely poorly	0	9	3	
Very poorly	4	4	2	
Quite poorly	3	4	4	
Quite well	13	4	5	
Very well	17	4	7	
Extremely well	23	5	4	
(Missing)	1	3	0	
(mean /SD levels)	4.92 (1.13)	3.21 (1.92)	3.92 (1.61)	F (2,112) = 13.64, p<0.0001****

DATA RELEVANT TO DISABLED SIBLINGS				
Age groups				
19 – 23	1	11	7	
24 – 29	18	7	8	
30 – 39	36	6	7	
40 – 65	6	8	4	
65+	0	0	0	
(Missing)	0	1	0	
(mean /SD levels)	32.62(6.30)	30.42(11.90)	28.92(11.02)	F (2,116) = 3.08, p = 0.04*****
Severity of disability				
Mild	2	6	0	
Moderate	31	7	11	
Severe	21	13	13	
Profound	5	6	2	
Missing	2	1	0	
(mean /SD levels)	2.50 (0.71)	2.65 (0.98)	2.65 (0.63)	F (2,114) = 0.44, p = 0.65

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*Tukey's post hoc analysis showed the ASD group had significantly more females than the DS group (mean difference =0.24, se = 0.09 p = 0.03).

**Despite the one-way ANOVA showing a difference between the groups overall, on closer examination Tukey's post-hoc analysis did not reveal any specific differences between the groups on the age-group they reported.

***Tukey's post hoc analysis showed a significant difference between DS and ASD, whereby the siblings of DS individuals perceived their mother as being better adjusted to having a child with disabilities than those mothers who had a child with ASD (mean difference = 1.05, se = 0.33, p =.006). The same pattern applied, whereby siblings of PWS individuals perceived their mothers as better adjusted than those with ASD (mean difference = 1.08, se = 0.40, p = .02). There was no significant difference in the findings between DS and PWS perception of maternal adjustment.

**** Tukey's post hoc analysis showed a significant difference between DS and ASD, whereby the siblings of those with DS perceived their father as being better adjusted to having a child with disabilities than those fathers who had a child with ASD (mean difference = 1.70, se = 0.33, p<.0001). Also the siblings of DS individuals perceived their fathers as better adjusted than those with PWS (mean difference = 0.95, se = 0.35, p = .02). There was no significant difference in the findings between ASD and PWS perception of paternal adjustment.

***** Tukey's post hoc analysis showed that the differences between the ages of the disabled siblings did not carry through to significance when closely examining the mean scores.

There were no significant differences between the groups on the variables of age, current relationship satisfaction, or whether the SDI was older or younger than their disabled sibling. When the disabled sibling was examined using Tukey's post-hoc analysis there was no significant differences between the levels of severity of the disability between the groups.

2.2.2 Measures

Demographic information

The demographic information for both groups is displayed in Tables 3.1 and 3.2. This majority of the information is self-explanatory but the information for socio-economic status

was categorised using the British Office for National Statistics scale (Hall, 2006): Examples of this include classification title 1 – doctors, lawyers, professors; classification 2 – teachers, nurses, journalists; classification 3 – secretaries, firemen; classification 4 – builders, hairdressers; classification 5 – train drivers, plumbers; classification 6 – postmen, care assistants; classification 7 – bus drivers, cleaners; classification 0 – students, long-term disabled, housewives/husbands, retired, etc.

For the SDI group the question on perception of maternal and paternal adjustment; scored on a Likert scale from 1, which meant that the mother or father was perceived as coping extremely well, with the disability incorporated into family life to 6, where the parent was perceived as responding extremely poorly to the disability and acted as if it was an inconvenience and made little or no allowances within their life to accommodate it.

The Hospital Anxiety and Depression Scale (HADS, Zigmond & Snaith, 1983)

The HADS was used to assess affective symptoms. It is a 14-point, self-report scale, which assesses both depression and anxious symptomatology, with scores above 7 indicating borderline problems and 11+ scores indicating clinical levels. The reasoning behind the use of the HADS was that it was suitable for use in a non-psychiatric setting (Snaith, 2003), which applied to the current set of participants, and it has proven reliability and validity (Bjelland et al. 2002; Herrmann, 1997). My study had high reliability for both anxiety and depression (Cronbach's alpha for SDI group anxiety .84, depression .70: Control group anxiety .86, depression .80). Also pertinent was the shortness of the measure, which consists of 7 questions for each scale, hopefully meaning participants would be more likely to complete the form. Further, the anxiety and depression scales were clearly delineated, making it easier to assess which affective symptoms were evident within the different participant groups. In addition, the data that was provided from the HADS for the main anxiety and depression variables, was continuous, which allows for more in-depth statistical analysis than other data would allow for. This study mainly used this continuous approach, where the total scores on both the anxiety and depression subscales were used as opposed to the categorical sub-scales.

Hazan and Shaver's (1986) adapted measure of the Descriptions of Parental Caregiving Style (DPCS, unpublished manuscript in Collins & Read, 1990)

This six item scale assesses participants' perceptions of the parental care-giving style that they received by rating the similarity of the statements made in relation to their perception of their mother and father's style of parenting (see Appendix C). They rated three paragraphs for similarity to their parents' styles, yielding warm, cold or inconsistent scores. There were statements made regarding each style and the participants answered each question twice, once for the mother and once for the father. The statements included, for example, 'he /she was good at knowing when to be supportive' and 'our relationship was almost always comfortable' for warm parenting; 'he /she was fairly cold and distant, or rejecting, not very responsive; I wasn't her highest priority, her concerns were often elsewhere; it's possible that she would just as soon not have had me' for cold parenting and 'he / she was noticeably inconsistent in her reactions to me, sometimes warm and sometimes not; she had her own agendas which sometimes got in the way of her receptiveness and responsiveness to my needs; she definitely loved me but didn't always show it in the best way' for inconsistent parenting. They were rated using a 7 point Likert scale, where 1 means strongly disagree with the paragraph to 7, which means strongly agree; the participants were obliged to give a score for every paragraph.

Experiences in Close Relationships (ECR, Brennan, Clark & Shaver, 1998)

The ECR is a 36-point scale that is rated with regard to an important relationship partner in the participant's life. The items assess the two attachment dimensions: attachment-related avoidance or attachment-related anxiety. The 18 items about attachment-related avoidance measure how the participant rates feelings of discomfort with closeness and the 18 items on the anxiety scale rate how someone feels about abandonment and the need for closeness within a relationship. Some of the questions asked included "I prefer not to show a partner how I feel deep down" and "I worry about being abandoned". The participants responded using a 7-point Likert scale, scoring 1 for 'Disagree strongly' to 7 for 'Agree strongly'. In the current study the Cronbach's alpha was high for both sub-scales for both the SDI and the control group (Avoidant: $\alpha = 0.93$ and 0.89, respectively; Anxious: $\alpha = .86$ and 0.91, respectively). The ECR can also be used to convert the attachment dimensions into the attachment categories of Secure, Fearful, Preoccupied or Dismissive, this, however, only allows for dichotomous scoring.

The International Personality Item Pool (IPIP) (Goldberg, 1999)

This 50-point scale, available in the public-domain (Goldberg et al. 2006), was used to assess participants' position on the Big 5 traits of Extraversion, Agreeableness, Conscientiousness, Neuroticism and Openness to Experience (see Appendix C). Typical questions to establish the participants' strength on the trait were "Am the life of the party", "Feel little concern for others", "Am always prepared", "Get stressed out easily" and "Have a rich vocabulary". The participants responded using a 5-point Likert scale ranging from 'very inaccurate' to 'very accurate'. The respective Cronbach alpha statistics for the Big 5 traits were .88, .81, .81, .89 & .80, respectively for the SDI and .73, .79, .78, .87 & .79, respectively for the control group.

2.2.3 Procedure

Disability charities, such as SIBS, the Down's syndrome Association, the National Autistic Society, the Prader-Willi Society and some smaller charities were contacted to ascertain their agreement in accessing their member databases to search for potential sibling of disabled individuals to act as participants. They would then either post questionnaires directly to potential participants or they would advertise for participants via their newsletters or websites (see Appendix E for copy of advertising brief) and then either post the questionnaire, with attached letter of request (see Appendix F) and information sheet (see Appendix G) or ask me to email them a copy depending upon what was requested. The participants would then privately complete as much of the questionnaire as they wished and return it to the Psychology Department at the University of Chester in the pre-addressed envelope or email the completed questionnaire. The postal responses were guaranteed anonymity due to the envelopes being shuffled with others before being opened for data analysis. A similar system applied to the emailed versions; they would be printed off, alocated a number and the information recorded from there. The control group was contacted more directly on the basis of their matching power to the sibling group but they were mainly sent directly to the participant. The exception to this was when the participant agreed to participate through one of the local businesses and they would take a questionnaire and envelope from the supply the business had available and post it back directly.

When the completed questionnaires had been returned, the individual measures were then separately recorded on SPSS version 14 data sheets, to then be collated on a further SPSS sheet, together with the demographic information recorded. The completion of the data included reversal of scoring for relevant items on the ECR and IPIP scales. The SDI group

participants were numbered when entered on to the spreadsheets and the control group participants when they were matched were given the same corresponding number and entered on to a separate spreadsheet. When all the data had been entered a new spreadsheet was created with the data from both groups. This made it possible to examine every participant and their control, which is particularly relevant to Chapter six.

For ease of data processing it was decided to recode marital status data, whereby married and co-habiting were collapsed into one group, as were divorced and separated. This was because marital status was not a critical variable in the analysis, other than as a factor in pairing the reference group with the control group, and it was felt that the commitment to the relationship would be similar in both these instances.

When the demographic variables were examined it was decided that, for parsimonious reasons, only the demographic variables that were significant in being correlated with anxiety and depression would then go forward as controlling variables for the mediation analysis; this was to increase statistical power (Hastings & Brown, 2002; Orsmond & Seltzer, 2007a). It was necessary to use any significant demographic variables found as control variables in the mediation analyses in order to give an accurate reflection of the attachment and personality variables involved in the reporting of affective symptomatology. Failure to do so could lead to biased co-efficients being reported, which could skew the results.

Moderation analysis was applied to the demographic variables of gender, age, relationship satisfaction, SES and educational attainment, in order to ascertain if the level of one of these demographic variables could alter the direction of the relationship between having a disabled sibling and anxiety and /or depression (see paragraph 3.2.5). Clearly, a moderating model could not be used for factors pertaining exclusively to the SDI group because there was no control group to use, whereby ‘having a disabled sibling’ could be used as a predictor variable. Instead, it was decided to use predictors of anxiety and depression based on bivariate correlations. The variables that were initially examined were severity of the disability, severity of the prognosis of the disability, where the disabled sibling now resides, if the SDI was now the primary carer, how well the parents were perceived to have adjusted to their child with disabilities and if the SDI was younger or older than the sibling with disabilities.

2.2.4 Design and analysis

The study was a cross-sectional, self-report study design. SPSS programmes (versions 14 and 17) were used to calculate the descriptive statistics and thereafter differences between the SDI and control groups were sought using either the McNemar test of proportions for frequency data and one-way ANOVAs for continuous data; Tukey's post-hoc analyses were then applied when necessary, in order to establish where the exact differences were to be found, correlation analyses and multiple regression analyses were also carried out. If there were any significant differences between the groups, these variables would then go on for further analysis; the demographics, particularly would be used as controlling variables in the analyses that followed.

2.2.5 Moderation analysis

In order to establish if an interaction effect between having a disabled sibling and the reporting of anxiety and /or depression symptomatology was dependent upon the level of further variables, moderation analysis was applied (Baron & Kenny, 1986). This should help to explain whether the demographic variables of gender, age, relationship satisfaction, socio-economic status or educational attainment will moderate the causal effect of having a disabled sibling on anxiety and /or depression symptomatology (Frazier, Tix & Barron, 2004; Kenny, 2009). Certain criteria for design, measurement and analysis had to be considered due to the characteristic problem of low statistical power in moderated multiple regression analysis (Aguinis & Gottfredson, 2010). The potential design issue of sample size was also considered; the problem mainly arises when the sample subgroup proportions are unequal (a 50 /50 population base is optimum); this was addressed by having exactly the same amount of participants in the SDI and control group so, therefore, there should be no decrease in power. Scale 'coarseness' was also an important point; this was where the DV (or outcome variable) did not have enough response options, thus reducing the correlation with the IV (or predictor variable), whereby it would result in a loss of power (Russell & Bobko, 1992, as cited by Frazier et al. 2004). Ideally the outcome variable should have the same or more response options than the product of the predictor and moderator variables. This meant that this study often had reduced power because the response options on the HADS was a 4-point Likert scale (Frazier et al. 2004); however, despite power being lost through the coarseness of lack of response options, the HADS was still chosen as the best affective measure because of

its high reliability and validity in measuring anxiety and depression, particularly in a non-clinical setting (Bjelland, Dahl, Haug & Neckelmann, 2002; Herrmann, 1997; Snaith, 2003).

The continuous variables were standardised (*z*) because it was then easier to plot significant moderator effects and it made it easier to interpret the effects of the predictor and moderator variables, due to a meaningful zero point (Frazier et al. 2004). It was also decided to code the categorical variables as dummy variables because this type of coding is ideally used when comparisons with a control group are required (Frazier et al. 2004). Moderation analysis was used to establish if there was a directional effect between SDI and anxiety and/or depression symptomatology with the addition of the theoretically based interaction variable (Baron & Kenny, 1986; Cohen et al. 2003, as cited by Frazier et al. 2004) of the demographic variables of gender, age, relationship satisfaction, socio-economic status and attained educational levels.

2.2.6 Mediation analysis

The established measures of perceived parenting styles, attachment styles and personality traits were also used in order to ascertain if they could explain the relationship between having a disabled sibling and the self-reported HADS anxiety and depression affective disorders through mediation analysis. Mediation analysis was carried out to establish if perceived parenting style, attachment styles or personality traits could theoretically and statistically explain if they were factors through which having a disabled sibling could influence anxiety and depression symptomatology (Baron & Kenny, 1986). They were examined as separate models. However, for parsimonious reasons only the variables on which the SDI group significantly differed from the control group went forward for further analyses (Orsmond & Seltzer, 2007a). Further, the demographic variables shown to have significant relationships with anxiety and /or depression symptomatology were retained as first-step variables in the mediation process (Hastings & Brown, 2002).

According to Baron and Kenny (1986) and Kenny (2009) four criteria need to be met in order to show that the mediating variables (M) of perceived parenting, attachment styles or personality traits would mediate the association between having a disabled sibling (the predictor variable (X)) and the affective disorders of anxiety and depression (the outcome variables (Y) (see Figure 2.1)). The variables should be significantly associated with each

other; if they were not then path C could be explained as the 'total effect', where having a disabled sibling had a complete effect on the affective disorders and was not influenced by any of the mediating variables. However, if any of them were a complete mediating influence, whereby having a disabled sibling would no longer affect anxiety and depression after the mediating variables had been controlled for then we could expect to see path C' as zero. If partial mediation was the end result when using the above variables as a mediating variables, we would expect to see the path reduced in absolute size but still different to zero.

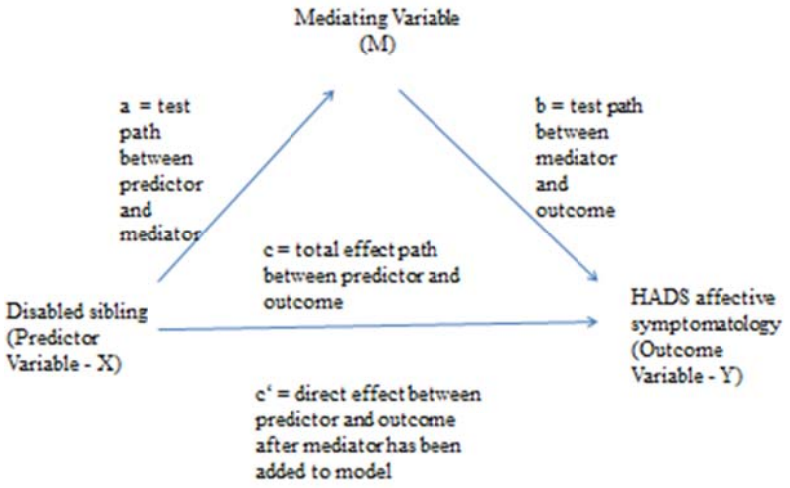

Figure 2.1: Mediation diagram explaining outcome variable (Y – affective disorders); predictor variables (X - disabled sibling); mediating variable (M – mediator variables); C' = direct effect path; a + b = test paths; C = total effect path between predictor variable and outcome variable before the addition of mediating variable (Kenny, 2009).

Demographic variables that were revealed as having significant relationships when testing for differences between the SDI and control group were used as first-step variables for the HADS anxiety and depression symptomatology when running the hierarchical multiple regression tests for mediation analyses. McNemar test of proportions were used for the frequency data of gender, age groups, relationship satisfaction, socio-economic status, educational attainment, the attachment categories and borderline and clinical caseness anxiety and depression. Throughout the thesis, separate models were created for anxiety and depression symptomatology and also all of the mediating variables found to be significant,

for example, perceived parenting styles, attachment styles and personality traits. Mediation analysis was carried out using Pearson's correlations; thereafter, linear hierarchical regression analyses were used to test the mediation hypotheses. To do this the four criteria set by Baron and Kenny (1986) had to be met. Briefly these were that (1) having a disabled sibling (IV) should be significantly associated with the affective disorders (DV) under study, which was indicated by path c (see Figure 2.1); (2) having a disabled sibling (IV) should be significantly associated with perceived parenting style, attachment style or personality traits (MVs), which was indicated by path a (see Figure 2.1); (3) anxiety or depression symptomatology (DVs) should be significantly associated with either perceived parenting styles, attachment dimensions or personality traits (see Figure 2.1, path b); (4) after controlling for the mediating variable, the association between having a disabled sibling and the affective disorders should be reduced or no longer significant (see Figure 2.1, path c**')**. The independent variable was having a disabled sibling; this is a dichotomous variable, however, MacKinnon, Lockwood, Hoffman, West & Sheets (2002) found that dichotomous independent variables produced almost identical results to models that have continuous independent variables. The dependent variables will be anxiety symptomatology or depression symptomatology.

Despite the continuing popularity of Baron and Kenny's mediation model, more recent research has indicated that ideally to be fully accurate, this model requires a sample size of at least 20,886 (Fritz & MacKinnon, 2007). My study's sample size did not equate to this and so therefore it was then necessary to carry out Sobel tests (Preacher & Leonardelli, 2010). Sobel tests seek to establish if mediation is present by calculating the indirect effect of the predictor variable on the outcome variable via the mediator variable in order to establish if it is significantly different from zero; if it is significant then mediation is occurring (Fritz & MacKinnon, 2007; Preacher & Leonardelli, 2010). The sample size (N = 300) was large enough to use the Sobel test (Preacher & Leonardelli, 2010). The Sobel tests should support the findings from the Baron and Kenny mediation test in testing the significance of the indirect effect of the mediating variables on the relationship between having a disabled sibling and anxiety and depression symptomatology.

There were separate mediation models for each of the variables to establish if they mediated the relationship between having a disabled sibling and anxiety and depression. Data was excluded list-wise from the analysis if a participant from either the SDI or control group had not completed all the items from any of the frequency variables in the measures that were used and pairwise deletion was used for the missing data for correlational analyses.; however,

it should be noted that the exclusion was only for the particular item and not the whole data set from the participant in order to maintain statistical power. This did sometimes create a situation whereby the overall analyses was sometimes based on unequal sample sizes. However, all the data was missing variables were closely examined and it was discovered that none of the variables were systematically omitted and so inclusion of the rest of the data was considered admissible (Heller & Kramer, 2009). The exclusion was always noted in the N value. The alpha level for each of the hypotheses was set at $p \leq .05$.

Chapter 3

Results

3.1 Anxiety and depression symptomatology

Initially it was necessary to establish if there was a difference in HADS affective symptomatology between the groups. Table 3.1 clearly shows that the SDI group scores significantly higher on mean scores for both anxiety and depression.

Table 3.1: Anxiety and depression scores for SDI and control group

HADS (N SDI / N control group)	SDI Mean (SD)	Control Mean (SD)	One-way ANOVAs
Anxiety (149/150)	9.02 (4.23)	7.11 (3.98)	F (1,297) = 16.10, p <.0001
Depression (148 /150)	4.40 (3.02)	3.10 (2.89)	F (1,296) = 14.36, p <.0001

Table 3.2: Frequencies of borderline and clinical levels of anxiety and depression for the SDI and control groups

HADS (N = anx/depr)	SDI N = 149/148	Control 'N' N = 148/150	McNemar test results
Anxiety borderline	43	29	χ^2 (1) = 2.35, p = 0.13
Anxiety clinical	50	31	χ^2 (1) = 4.00, p = 0.04
Depression borderline	19	11	χ^2 (1) = 1.63, p = 0.20
Depression clinical	5	3	χ^2 (1) = 0.12, p = 0.72

Table 3.2 shows the number of participants scoring in the anxiety and depression borderline and clinical categories. The Table clearly demonstrates that the majority of both SDI and control group participants do not have clinical affective symptomatology. However, the Table does indicate that the SDI scored higher than the control group in every affective category; however, only the clinical levels for anxiety were significantly different between the two groups.

3.2 Demographic variables

3.2.1 Gender:

(Please see Table 2.1 for the demographic details on gender). When further analysis was carried out it showed that females scored higher than males in both groups for anxiety and depression (see Table 3.3). Interestingly, males and females in the SDI group scored higher on both measures of anxiety and depression symptomatology than the control group than their respective gender; furthermore SDI males had higher scorings on depression and similar anxiety symptomatology scores to control group females.

Table 3.3: Mean scores and standard deviations for male and female participants on anxiety and depression from the SDI and control groups

		N	Anxiety		Depression	
			Mean	(SD)	Mean	(SD)
SDI	- Male	33	7.22	(4.38)	3.72	(2.65)
	Female	117	9.51	(4.07)*	4.59	(3.10)**
Control	-Male	33	5.94	(3.12)	1.97	(1.61)
	Female	117	7.44	(4.15)	3.42	(3.09)

*= mean different from control group and SDI males at p <.05

**= mean different from control group at p <.05

There were significant differences between the genders from the SDI and the control group in reporting the effect for HADS anxiety ($F(3,295) = 9.29$, $p < .0001$) and for HADS depression ($F(3,294) = 7.93$, $p < .0001$). When Tukey's post hoc analysis was carried out it supported the descriptive statistics findings and showed that the differences were with the females from the SDI group in reporting significantly higher anxiety symptomatology than the males from the SDI group (mean difference = 2.29, SE= .81, p =.03), the males from the control group (mean difference = 3.57, SE= .80, p <.0001) and the females from the control group (mean difference = 2.04, SE= .53, p =.001). Likewise, the females from the SDI group

reported significantly higher levels of depression symptomatology than the males from the control group (mean difference = 2.64, SE= .58, p <.0001) and the females from the control group (mean difference = 1.20, SE= .38, p =.01). There was a trend shown for a difference between the males reporting on depression symptomatology with the SDI males reporting higher levels (p=.07) than the control males.

Moderation Analysis

When moderation analysis was carried out to ascertain if there was an interaction between anxiety and gender (see Table 3.4), it showed that the unstandardised regression co-efficient for gender was 0.45 (p = .001). The unstandardised regression co-efficient for having a disabled sibling was 0.45 (p <.0001); this means that there was a significant positive relationship between gender and anxiety and also between having a disabled sibling and anxiety. However, the unstandardised regression co-efficient for the interaction term was not significant (p =.49, ns), which indicated that there was no interaction or moderating effect of gender upon the relationship between having a disabled sibling and anxiety. This, however, might be accounted for by the unequal weighting between the male and female groups, with 22% of the participants being male and 78% female (Aguinis & Gottfredson, 2010). It should be noted that the $R^2\Delta$ associated with the interaction term was 0.00, which indicated that the interaction between having a disabled sibling and gender explained no additional variance in anxiety scores over and above the 9% explained by the independent effects of having a disabled sibling and gender.

Table 3.4: Testing moderating effects of gender on the relationship between having a disabled sibling and standardised scores for anxiety, using hierarchical multiple regression

Step and variable	*B*	*SE B*	95% CI	*β* (p-value)	$R^2\Delta$ (p-value)
Step 1					
Disabled Sibling	.45	.11	.23, .67	.23 (<.0001)	
Gender	.45	.14	-.19, .72	.19 (.001)	.09 (<.0001)
Step 2					
Disabled Sib x Gender	.19	.27	-.34, .72	.09 (.49, ns)	.00 (.49, ns)

Key: CI = confidence interval; ns = non-significant; Gender Dummy Coding (males coded 0, females coded 1); Disabled Sibling Dummy Coding (Non-Disabled Sibling coded 0, Disabled Sibling coded 1)

Table 3.5: Testing moderating effects of gender on the relationship between having a disabled sibling and standardised scores for depression, using hierarchical multiple regression

Step and variable	*B*	*SE B*	95% CI	*ß* (p-value)	$R^2\Delta$ (p-value)
Step 1					
Disabled Sibling	.43	.11	.21, .65	.21 (<.0001)	
Gender	.38	.14	.12, .65	.16 (.005)	.07 (<.0001)
Step 2					
Disabled Sib x Gender	-.19	.27	-.72, .34	-.09 (.48, ns)	.00 (.48, ns)

Key: CI = confidence interval; ns = non-significant; Gender Dummy Coding (males coded 0, females coded 1); Disabled Sibling Dummy Coding (Non-Disabled Sibling coded 0, Disabled Sibling coded 1)

Similarly to the anxiety model, the moderating effect of gender on depression and having a disabled sibling was non-significant (see Table 3.5). Table 4.5 shows that the unstandardised regression co-efficient for gender was 0.38 (p = .005). The unstandardised regression co-efficient for having a disabled sibling was 0.43 (p <.0001); this means that there was a significant positive relationship between gender and depression and also between having a disabled sibling and depression. There was, however, no increase in the explained variance when the interaction term was used, which indicates that there was no interaction or moderating effect of gender upon the relationship between having a disabled sibling and depression. The opposite patterns shown in the Tables when the interaction term is applied is due to the coding system for the dichotomous variables and the higher number of females compared to males within the cohort. It indicates that females moderate the causal effect of having a disabled sibling on anxiety to a greater extent than males (non-significant) but that the moderating effect of males is higher for depression than for anxiety (non-significant).

3.2.2 Age

(Please see Table 2.1 for the demographic details on age). When the relationship between age and anxiety and depression was examined for both groups it showed that there

was no significant association between the SDI group and either anxiety or depression. Likewise, there was no association between the control group and anxiety but there was a significant association between the control group and depression (r = -.22, p =.009). This indicated that the younger the participant, the more vulnerable they were to depression symptomatology.

Moderation Analysis

When examining the output for a moderating effect of age on anxiety symptomatology (see Table 3.6), it showed that the unstandardised regression co-efficient for age was $B = 0.03$ (p = .57), which was not significant at the p <.05 level. The unstandardised regression co-efficient for having a disabled sibling was 0.47 (p <.0001); meaning that there was a significant positive relationship between having a disabled sibling and anxiety in this sample; whereas age has no effect upon anxiety. The unstandardised regression co-efficient for the interaction term was -.20 (p = .10, ns), indicating that there was a trend towards an interaction effect of age between having a disabled sibling and anxiety, where older participants reported fewer anxiety symptoms. Further, the $R^2\Delta$ associated with the interaction term was 0.09, indicating that the interaction between having a disabled sibling and age explains approximately an additional 1% of the variance in anxiety scores over and above the 5% explained by the independent effects of having a disabled sibling and age alone.

Table 3.6: Testing moderating effects of age (standardised scoring) on the relationship between having a disabled sibling and anxiety, using hierarchical multiple regression

Step and variable	*B*	*SE B*	95% CI	*ß* (p)	$R^2\Delta$ (p)
Step 1					
Disabled Sibling	.47	.12	.24, .70	.23 (<.0001)	
Age (*z* score)	.03	.06	-.08, .15	.03 (.57, ns)	.05 (<.0001)
Step 2					
Age x Disabled Sib	-.20	.12	-.42, .03	-.13 (.10, ns)	.01(.10, ns)

(Non-Disabled Sibling coded 0, Disabled Sibling coded 1)

Table 3.7: Testing moderating effects of age (standardised scoring) on the relationship between having a disabled sibling and depression, using hierarchical multiple regression

Step and variable	*B*	*SE B*	95% CI	*β* (p)	$R^2\Delta$ (p)
Step 1					
Disabled Sibling	.49	.11	.27, .71	.25 (<.0001)	
Age (*z* score)	.17	.06	.06, .28	.17 (.003)	.08 (<.0001)
Step 2					
Age x Disabled Sib	-.06	.12	-.29, .17	-.04 (.60, ns)	.00 (.60, ns)

Disbl Sib = disabled sibling; CI = confidence interval; ns = non-significant; Disabled Sibling Dummy Coding (Non-Disabled Sibling coded 0, Disabled Sibling coded 1)

The moderating effect of age and having a disabled sibling on depression was not significant (see Table 3.7); the unstandardised regression co-efficient for the interaction was -0.06, which was not significant at the $p < .05$ level ($p = .60$). There was also no increase in the $R^2\Delta$ associated with the interaction term. However, it should be noted that there were significant independent effects of having a disabled sibling on depression and also age in this sample.

3.3.3 Relationship satisfaction:

(Please see Table 2.1 for demographic details on marital status and relationship satisfaction). For those who were in relationships, the tendency was that they were of long duration; whereby 57% of the respondents for the SDI and 49% for the control group were in relationships of longer than five years. When correlational analysis was done, it was interesting to note that higher satisfaction levels are negatively associated with anxiety for the SDI group ($r = -.38$, $p < .0001$) and negatively associated with both anxiety ($r = -.20$, $p = .03$) and depression ($r = -.20$, $p = .03$) for the control group. Surprisingly, when the divorce /separation variable was correlated with anxiety and depression there were no significant findings for either group.

A point of interest is that it transpired that in the SDI group, 23.3% had experienced parental divorce; this was marginally less than the 25% reported in the control group. However, there was no significant difference between the groups and no significant association between parental divorce and anxiety and depression for either group. It was interesting to note that parental contact following divorce had a significant negative association with anxiety and depression symptomatology for the control group (r = -.38, p .03; r =-.39, p = .02, respectively); there were no significant associations between these variables for the SDI group.

Moderation Analysis

The moderating effects of relationship satisfaction and having a disabled sibling upon anxiety and depression were non-significant (see Tables 3.8 and 3.9). The unstandardised regression co-efficients for the interaction for anxiety was *B* = -0.16 (p = .60) and for depression was *B* = 0.04 (p = .77), neither of which were significant at the p <.05 level. There was also no increase in the $R^2\Delta$ associated with the interaction term for either anxiety or depression. However, it should be noted that the independent effect size that relationship satisfaction had upon ameliorating anxiety symptoms was greater than the effect size of having a disabled sibling upon anxiety symptoms; conversely, the effect size of having a disabled sibling on depression was greater than the ameliorating independent effect of relationship satisfaction upon depression.

Table 3.8: Testing moderating effects of relationship satisfaction (standardised scoring) on the relationship between having a disabled sibling and anxiety, using hierarchical multiple regression

Step and variable	*B*	*SE B*	95% CI	*β* (p)	$R^2\Delta$ (p)
Step 1					
Disabled Sibling	.45	.13	.20, .70	.22 (.001)	
RShip Stfcn (*z* score)	-.30	.07	-.43,-.17	-.29 (<.0001)	.13 (<.0001)
Step 2					
RShpStfcn xDisblSib	-.16	.13	-.42, .09	-.12 (.60, ns)	.00 (.21, ns)

Key:Disbl Sib = disabled sibling; RShip Stfcn = relationship satisfaction; CI = confidence interval; ns = non-significant; Disabled Sibling Dummy Coding (Non-Disabled Sibling coded 0, Disabled Sibling coded 1)

Table 3.9: Testing moderating effects of relationship satisfaction (standardised scoring) on the relationship between having a disabled sibling and depression, using hierarchical multiple regression

Step and variable	*B*	*SE B*	95% CI	*β* (p)	$R^2\Delta$ (p)
Step 1					
Disabled Sibling	.43	.13	.17, .69	.21 (.001)	
RShipStfcn (*z* score)	-.19	.07	-.32,-.06	-.18 (.004)	.08 (<.0001)
Step 2					
RShpStfcn xDisblSib	.04	.13	-.22, .30	.03 (.77, ns)	.00 (.77, ns)

Disbl Sib = disabled sibling, RShip Stfcn = relationship satisfaction, CI = confidence interval, ns = non-significant, Disabled Sibling Dummy Coding (Non-Disabled Sibling coded 0, Disabled Sibling coded 1)

3.2.3 Social Economic Status:

(Please see Table 2.1 for details on the demographic variables for socio-economic status). When further analysis was carried out it showed that there were no significant associations found between anxiety and depression symptomatology and either socio-economic band

(Hall, 2006) or the amount of annual income for the SDI group. On the other hand, the control group reported that those in the lower socio-economic bands tend to be more likely to report depressive symptomatology (r-.21, p = .02); however, there is no association between annual income and anxiety and depression and annual income for the control group.

Moderation Analysis:

When moderation analysis (see Tables 3.10 and 3.11) was carried out no moderating effects of higher levels of SES on the relationship between having a disabled sibling and anxiety and /or depression symptomatology were found. The independent effect for SES upon anxiety and depression was non-significant for both models.

Table 3.10: Testing moderating effects of SES (measured by annual income (standardised scoring) on the relationship between having a disabled sibling and anxiety, using hierarchical multiple regression

Step and variable	*B*	*SE B*	95% CI	*β* (p)	$R^2\Delta$ (p)
Step 1					
Disabled Sibling	.45	.11	.23, .67	.23 (<.0001)	
SES (*z* score)	-.08	.06	-.20, .03	-.08 (.14, ns)	.06(<.0001)
Step 2					
SES xDisabled Sib	.02	.11	-.20, .25	.02 (.85, ns)	.00 (.85, ns)

Key: CI = confidence interval, ns = non-significant, Disabled Sibling Dummy Coding (Non-Disabled Sibling coded 0, Disabled Sibling coded 1)

Table 3.11: Testing moderating effects of SES (measured by annual income (standardised scoring) on the relationship between having a disabled sibling and depression, using hierarchical multiple regression

Step and variable	*B*	*SE B*	95% CI	*β* (p)	$R^2\Delta$ (p)
Step 1					
Disabled Sibling	.43	.11	.20, .65	.21 (<.0001)	
SES (*z* score)	-.08	.06	-.19, .03	-.08 (.16, ns)	.05 (<.0001)
Step 2					
SES xDisabled Sib	.13	.11	-.10, .35	.09 (.26, ns)	.00 (.26, ns)

Disbl Sib = disabled sibling, SES = socio-economic status, CI = confidence interval, ns = non-significant, Disabled Sibling Dummy Coding (Non-Disabled Sibling coded 0, Disabled Sibling coded 1)

3.2.5 Education Levels:

(Please see Table 2.1 for demographic details on education). When correlation analyses were carried out, there was no significant effect found between higher education levels and symptomatology for anxiety and depression for the SDI group, however, in contrast, the control group showed a negative association between higher educational levels and symptomatology for depression (r = -.25, p =.002) and again a negative association between higher paternal educational levels and symptomatology for depression (r = -.23, p =.03).

Moderation Analysis

However, when examining the results for moderation, there was found to be no moderating effect of higher levels of educational attainment on the relationship between having a disabled sibling and anxiety and /or depression symptomatology (see Tables 3.12 and 3.13). However, despite there being no interaction between the variables, a clear effect of educational attainment levels can be seen to have an ameliorating effect upon depression (see Table 3.13).

Table 3.12: Testing moderating effects of educational attainment level (standardised scoring) on the relationship between having a disabled sibling and anxiety, using hierarchical multiple regression

Step and variable	*B*	*SE B*	95% CI	*β* (p)	$R^2\Delta$ (p)
Step 1					
Disabled Sibling	.49	.12	.26, .72	.42 (<.0001)	
EducLevel (*z* score)	-.04	.06	-.16, .07	-.04 (47, ns)	.06 (<.0001)
Step 2					
EducLevel xDisblSib	.09	.12	-.15, .32	.06 (.47, ns)	.00 (.47, ns)

DisblSib = disabled sibling, EducLevel = educational attainment level, CI = confidence interval, ns = non-significant, Disabled Sibling Dummy Coding (Non-Disabled Sibling coded 0, Disabled Sibling coded 1)

Table 3.13: Testing moderating effects of educational attainment level (standardised scoring) on the relationship between having a disabled sibling and depression, using hierarchical multiple regression

Step and variable	*B*	*SE B*	95% CI	*β* (p)	$R^2\Delta$ (p)
Step 1					
Disabled Sibling	.49	.12	.26, .71	.25 (<.0001)	
EducLevel (*z* score)	-.16	.06	-.27,-.05	-.16 (.006)	.07 (<.0001)
Step 2					
EducLevel xDisblSib	.17	.12	-.06, .40	.11 (.14, ns)	.00 (.14, ns)

Disbl Sib = disabled sibling, EducLevel = educational attainment level, CI = confidence interval, ns = non-significant, Disabled Sibling Dummy Coding (Non-Disabled Sibling coded 0, Disabled Sibling coded 1)

3.2.6 Demographic variables that specifically apply to the SDI group

Please see Table 2.2 to examine the demographic details specific to the SDI group. The bivariate correlations for the factors that specifically applied to the siblings of the disabled group were examined (see Table 3.14) to assess the relationship with anxiety and depression.

Table 3.14: Correlations between scores and specific factors relating to the SDI group (N =150)

	HADS Anxiety (r value)	(p value)	HADS Depression (r value)	(p value)
Severity of disability	.04	(n.s)	-.21	(.04)
Medical prognosis	.24	(.02)	.02	(n.s)
Residence	-.02	(n.s)	.01	(n.s)
Primary Carer	.16	(n.s)	.20	(.05)
Mother Adjusted	-.25	(.02)	-.18	(n.s.)
Father Adjusted	-.22	(.04)	-.29	(.006)
Younger/Older*	-.20	(.03)	-.22	(.02)

Key: (younger sibling coded 0: older sibling coded 1)

Table 3.14 clearly shows a significant positive correlation between anxiety symptomatology, the worse the prognosis of the disability and being younger than the disabled sibling, whereas higher maternal and paternal adjustment were negatively associated with anxiety symptomatology. The SDI being the primary carer for their disabled sibling and being younger than the disabled sibling were positively associated with depression symptomatology, while the severity of the disability and paternal adjustment were negatively associated with depression symptomatology.

Hierarchical multiple regression analyses was then carried out to establish which variables were predictive of anxiety and depression within this cohort. Table 3.15, step 2

illustrated that higher levels of anxiety were predicted by poorer levels of prognosis for the disabled sibling. Likewise, the younger sibling was significantly more predictive of anxiety than the older sibling. Lastly, being the primary carer and the less severe the disability are both predictors for depression; however, higher levels of paternal adjustment were significantly predictive of reduced depression symptomatology.

Table 3.15: Multiple regression analysis to ascertain specific predictive factors contributing to anxiety and depression symptomatology in the SDI (N: anxiety = 149/depression = 148)

	Anxiety			Depression		
	ΔR^2	ΔF (p-value)	β(p-value)	ΔR^2	ΔF (p-value)	β (p-value)
Step 1	.12	1.94 (.08, ns)		.18	3.01 (.01)	
Severity			.02 (ns)			-.25 (.02)
Prognosis			.20 (ns)			-.04 (ns)
Residence			-.10 (ns)			-.05 (ns)
Primary Carer			.12 (ns)			.21 (ns)
Mother Adjusted			-.14 (ns)			-.03 (ns)
Father Adjusted			-.10 (ns)			-.29 (.02)
Step 2	.06	6.04 (.02)		.06	6.05 (.02)	
Severity			.02 (ns)			-.25 (.02)
Prognosis			.21 (.05)			-.02 (ns)
Residence			-.06 (ns)			-.02 (ns)
Primary Carer			.13 (ns)			.21 (.05)
Mother Adjusted			-.17 (ns)			-.07 (ns)
Father Adjusted			-.08 (ns)			-.26 (.02)
Younger/older			-.25 (.02)			-.25 (.02)

Key: (younger sibling coded 0: older sibling coded 1)

Due to the results of the severity of the diagnosis going in the unexpected direction of the less severe the disability the more likely the SDI is to report depression symptomatology, it was decided to study the severity scores in more detail. I therefore tried to establish if there were any significant differences between the mean scores on the severity measure when examining the key measures of the thesis. The results found in Table 3.16 show that one-way ANOVAs found no significant differences due to the level of severity of the sibling's disability; this was confirmed through Tukey's post-hoc analysis also finding no significant differences between the different levels of severity and the established measures.

Table 3.16: Means for the SDI groups anxiety, depression, perceived inconsistent mothering, attachment-related anxiety, neuroticism and extraversion levels depending upon the severity of siblings disability

	Mild N =10	Moderate N =58	Severe N =58	Profound N =21	One-way ANOVA
	Mean /SD	Mean /SD	Mean /SD	Mean /SD	
HADSAnx	8.20 (3.88)	9.53 (4.94)	8.35 (3.37)	9.67 (4.26)	F (3,142) = 1.04, p = 0.38
HADSDepr	4.50 (4.03)	4.54 (2.95)	4.35 (3.07)	3.95 (2.87)	F (3,141) = 0.02, p = 0.90
IncnMother	2.70 (2.11)	2.82 (2.08)	3.27 (2.27)	2.40 (1.93)	F (3,139) = 0.99, p = 0.41
AttachAnxiety	3.42 (1.26)	3.78 (1.38)	3.58 (1.14)	3.82 (1.20)	F (3,140) = 0.46, p = 0.71
Neuroticism	2.93 (0.65)	3.22 (0.85)	3.11 (0.77)	3.35 (0.99)	F (3,143) = 0.78, p = 0.51
Extraversion	3.18 (0.74)	3.30 (0.80)	3.17 (0.79)	3.19 (0.80)	F (3,139) = 0.28, p = 0.84

Key: SD = standard deviation; HADSAnx = HADS anxiety symptomatology; HADSDepr = HADS depression symptomatology; IncnMother = perceived inconsistent mothering; AttachAnxiety = attachment-related anxiety.

3.3 Perceived parenting and attachment styles

3.3.1 Descriptive Statistics for Descriptions of Parental Caregiving Style Scale

Table 3.17 shows the descriptive statistics for the perceived parenting styles. The same pattern was followed for perceived mothering and fathering styles across the SDI and control groups, whereby most participants perceived a warm style of parenting, followed by inconsistent parenting and fewest participants rated their parents' style as cold. The minimum score possible to report for each of the DPCS questions was 1, and the maximum score was 7; it was noted that the full range was used for each question. One-way ANOVA tests were conducted to ascertain if there were differences between the sibling and control groups in terms of describing perceived parenting styles.

Table 3.17: Main descriptive statistics for Descriptions of Parental Caregiving Style variables for Siblings of Disabled Individuals versus control group

DPCS (N SDI / N control group)	SDI Mean (SD)	Control Mean (SD)	One-way ANOVA tests
Mother Warm (145/ 145)	5.57 (1.78)	5.89 (1.61)	F (1,288) =2.64, p = 0.11
Mother Cold (145/ 126)	1.77 (1.48)	1.83 (1.53)	F (1,269) =0.14, p = 0.71
Mother Inconsistent (146/ 128)	2.96 (2.14)	2.31 (1.88)	F (1,272) =6.96, p = 0.009
Father Warm (144/ 136)	4.89 (2.03)	5.29 (1.93)	F (1,278) =2.92, p = 0.09
Father Cold (144/ 119)	2.65 (2.13)	2.21 (1.85)	F (1,261) =3.08, p = 0.08
Father Inconsistent (145/ 124)	3.48 (2.25)	2.85 (2.08)	F (1, 267) = 5.60, p = 0.02

Table 3.17 shows that the SDI group report lower levels of warm mothering, cold mothering and warm fathering than the control group and higher levels of inconsistent mothering and fathering and also cold fathering than the control group. However, one-way ANOVA tests show that the only significant differences between the two groups was that there was a higher tendency for the SDI to rate both their mother and father as inconsistent in comparison to the control group; therefore, only these variables went forward for further analyses.

3.3.2 Descriptive statistics for Experiences in Close Relationships Scale

Table 3.18 shows that participants had higher mean scores on the anxious dimension than on the avoidant dimension. When the two groups were compared through one-way ANOVA tests to establish if they reported any differences between the groups on attachment related dimensions, it showed that there was a significant tendency for the SDI group to report higher attachment-related anxiety than the control group and consequently attachment-related anxiety went forward for further analysis. Despite the SDI group showing a stronger tendency towards attachment-related avoidance than the control group, it failed to reach significance and consequently did not go forward for further analysis. The minimum and maximum possible scores on the avoidant and anxious dimension were 1 and 7, respectively; it was noted that the SDI group scored from 1 to 6.28 for the avoidant dimension, the control group scored from 1 to 4.89. Table 3.19 also shows that, when broken down into categories, more participants were securely attached than the other categories. This held for both groups. However, there was a significantly higher tendency for the control group to report secure attachment styles than the SDI, while the SDI group reported significantly higher preoccupied attachment levels than the control group.

Table 3.18: Descriptive and inferential statistics for ECR dimensional variables for SDI versus control group

ECR (N SDI / N control group)	SDI Mean (SD)	Control Mean (SDI)	One-way ANOVAs
Avoidant (147/ 149)	2.96 (1.31)	2.70 (1.01)	F (1,294) =3.59, p= 0.06
Anxious (147/ 149)	3.68 (1.25)	3.07 (1.09)	F (1,294) = 19.89, p<0.0001

Table 3.19: Descriptive and inferential statistics for ECR categorical variables for SDI versus control group

Categories (Total N = 296)	SDI (N)	Control (N)	McNemar test results
Secure	46	72	χ^2 (1) = 5.30, p = 0.02
Fearful	38	31	χ^2 (1) = 0.52, p = 0.47
Preoccupied	39	19	χ^2 (1) = 6.22, p = 0.01
Dismissive	24	27	χ^2 (1) = 0.08, p = 0.78

3.4 Personality traits

3.4.1 Descriptive statistics for personality traits

As Table 3.20 shows both groups scored highest on the adaptive trait of agreeableness and lowest on neuroticism, however, the SDI group scored lower on extraversion, higher on neuroticism and openness and very similarly on agreeableness and conscientiousness than the control group. However, when one-way ANOVAs were applied only extraversion, neuroticism and openness showed significant differences between the SDI and control

groups, consequently only these three variables therefore went forward for further analyses. As there were no differences between the groups for agreeableness and conscientiousness and these variables were excluded from further analyses.

Table 3.20: Main descriptive statistics for IPIP variables for SDI versus control group

IPIP (N SDI / N control group)	SDI Mean (SD)	Control Mean (SD)	One-way ANOVAs
Extraversion (146/ 141)	3.23 (.78)	3.51 (.77)	F (1,285) =10.40, p = 0.001
Agreeableness (147/ 139)	4.08 (.59)	4.10 (.58)	F (1,286) =0.12, p = 0.73
Conscientious (143/ 136)	3.67 (.68)	3.62 (.61)	F (1,277) = 0.28, p = 0.60
Neuroticism (150/ 144)	3.18 (.82)	2.91 (.75)	F (1,292) = 8.50, p = 0.004
Openness (146/ 139)	3.70 (.61)	3.54 (.59)	F (1,283) = 5.55, p = 0.02

3.5 Perceived parenting styles, attachment-related anxiety and personality traits as mediators between having a disabled sibling and affective disorders

The proposed mediation models to try to establish which measures can explain the pathway between having a disabled sibling and anxiety and /or depression include the following principal variables: having a disabled sibling, the significant perceived parenting variables, attachment-related anxiety, extraversion, neuroticism and openness.To confirm the mediation requirements set by Baron and Kenny (1986) a series of correlations and linear, hierarchical regressions were performed, the results of which are as follows:

According to Baron and Kenny (1986), in order to ensure that the mediation analyses are valid, the first criterion required for perceived parenting variables, attachment-related anxiety and the significant personality traits to mediate the association between having a

disabled sibling and anxiety and depression, is that these variables should be significantly associated with having a disabled sibling. Table 3.21 shows that with the exception of perceived inconsistent fathering and HADS anxiety and depression and openness for HADS anxiety, this is the case; therefore, the first criterion was satisfied for perceived inconsistent mothering, attachment-related anxiety, extraversion, neuroticism and openness (openness only for HADS depression). However, perceived inconsistent fathering will be excluded from all further analyses and openness will be excluded from all further analyses that include HADS anxiety.

The demographic variables that are to act as controls were also added to the correlational analysis (see table 3.21). There were non-significant relationship found between HADS anxiety, age and educational qualifications, consequently, these demographic variables were excluded from further analyses that included HADS anxiety. Similarly, due to the non-significant relationship between HADS depression and educational qualifications, the education variable was excluded from all further analyses that included HADS depression. The dichotomous variables of gender and having a disabled sibling were also shown to be significant through one-way ANOVAs. The findings for gender, based on the whole cohort, were significant for HADS anxiety ($F(1,297) = 10.80$, $p = .001$) and HADS depression ($F(1,296) = 7.78$, $p = .006$). The One-way ANOVA results for having a disabled sibling and HADS anxiety ($F(1,297)$ 16.10, $p < .0001$) and HADS depression ($F(1,296) = 14.36$, $p < .0001$). Therefore, the demographic variables of gender and relationship satisfaction will go forward for further analyses for HADS anxiety and the variables of gender, age and relationship satisfaction for will go forward for HADS depression

Table 3.21: Correlations between the principal variables (N in brackets)

	HADS Anxiety (299)	HADS Depr (298)	Incns Moth (274)	Incns Fath (269)	Attach Anxiety (296)	Extrav (287)	Neurot (294)	Open (285)	Age (294)	R/ship stsfcn (228)	Educ Qual (295)
HADSAnxiety	---										
HADSDepress	.57***										
InconMothering	.15**	.15**									
InconFathering	.11	.07	.41***								
AttachAnxiety	.55***	.44***	.17**	.13*							
Extraversion	-.22***	-.36***	-.13*	.14*	-.23***						
Neuroticism	.69***	.47***	.28***	.23***	.54***	-.30***					
Openness	.06	-.12*	.09	.06	.01	.22***	.07				
Age	.00	.14*	.05	.01	-.10	-.08	-.07	-.04			
R/shipStsfaction	-.29***	-.18**	-.05	-.07	-.32***	-.01	-.29***	-.01	.02		
EducQualfcation	.02	-.10	-.12	.00	.03	.01	-.02	.37***	-.13*	.02	
Disabled Sibling	.23***	.22***	.16**	.14*	.25***	-.19**	.17***	.14*	-.14*	.00	.24***

Key: * Correlation is significant at the 0.05 level, ** Correlation is significant at the 0.01 level,

*** Correlation is significant at the 0.001 level.

The principal statistical analyses involved hierarchical regression methods; the results are summarised in Tables 3.22 to 3.30. Initially, the demographic variables of gender and relationship satisfaction were entered as control variables on the HADS anxiety model; gender, relationship satisfaction and age were entered into the regression model for HADS depression due to their significant association with the HADS scores. Subsequently, having a disabled sibling was entered into the separate models as a predictor variable at Step 2. Thereafter, in order to ascertain if perceived inconsistent mothering, attachment-related anxiety, extraversion, neuroticism or openness would act as a mediators between having a

disabled sibling and either HADS anxiety and / or depression, they were entered into separate models at the third step.

Baron and Kenny (1986) state that the mediating variables should be significant unique predictors of anxiety and /or depression symptom scoring and having a disabled sibling would no longer be significant after the mediators were added to the models. Therefore, if perceived inconsistent mothering, attachment-related anxiety or any of the personality variables were to significantly mediate the association between having a disabled sibling and either HADS anxiety or depression, the associations between having a disabled sibling and anxiety and depression should be reduced or be no longer significant. Each model will hereafter be examined separately.

3.5.1 Perceived inconsistent mothering

It is clear in Tables 3.22 and 3.23 that when at Step 3, perceived inconsistent mothering was added to the models, there were no significant results. The Tables show that there was no increase in the unique explained variance for either anxiety or depression and no significance in the unique standardised beta indicators for perceived inconsistent mothering. Therefore, perceived inconsistent mothering does not act as a mediator between anxiety and /or depression and having a disabled sibling.

Table 3.22: Hierarchical regression analysis examining the effects of having a disabled sibling and perceived inconsistent mothering upon HADS anxiety

Step and variable	*ß* (p)	R	F (p)	$R^2\Delta$ (p)	F Δ
Step 1		.32	11.25 (<.0001)	.10 (<.0001)	
Gender	.16 (.02)				
Relationship Satisfaction	-.26 (<.0001)				
Step 2		.39	12.27 (<.0001)	.05 (.05)	12.97
Gender	.15 (.02)				
Relationship Satisfaction	-.27 (<.0001)				
Disabled Sibling	.23 (<.0001)				
Step 3		.39	9.33 (<.0001)	.00 (.44, ns)	0.60
Gender	.15 (.02)				
Relationship Satisfaction	-.26 (<.0001)				
Disabled Sibling	.22 (<.0001)				
Inconsistent Mother	.05 (.44)				

Table 3.23: Hierarchical regression analysis examining the effects of having a disabled sibling and perceived inconsistent mothering upon HADS depression

Step and variable	*ß* (p)	R	F (p)	$R^2\Delta$ (p)	F Δ
Step 1		.24	4.09 (.008)	.06 (.008)	
Gender	.14 (.04)				
Relationship Satisfaction	-.14 (.04)				
Age	.03 (.10, ns)				
Step 2		.32	5.78 (<.0001)	.05 (.002)	10.29
Gender	.13 (.05)				
Relationship Satisfaction	-.15 (.03)				
Age	.13 (.05)				
Disabled Sibling	.22 (.002)				
Step 3		.33	4.80 (<.0001)	.00 (.34, ns)	0.91
Gender	.13 (.05)				
Relationship Satisfaction	-.15 (.03)				
Age	.13 (.06, ns)				
Disabled Sibling	.20 (.003)				
Inconsistent Mothering	.06 (.34, ns)				

3.5.2 Attachment-related anxiety

In order to ascertain if attachment-related anxiety mediated the relationship between having a disabled sibling and anxiety and /or depression, further hierarchical multiple regression analyses were carried out. The reasons behind doing this and the pattern of the way in which the predictors were added was the same as in the previous models (see Tables 4.24 & 4.25) but attachment-related anxiety replaced perceived inconsistent mothering.

Table 3.24: Hierarchical regression analysis examining the effects of having a disabled sibling and attachment-related anxiety upon HADS anxiety

Step/Variable	*β* (p)	R	F (p)	$R^2\Delta$ (p)	F Δ
Step 1		.32	13.17 (<.0001)	.10 (<.0001)	
Gender	.14 (.03)				
Relationship Satisfaction	-.28 (<.0001)				
Step 2		.39	13.38 (<.0001)	.05 (.001)	12.46
Gender	.15 (.02)				
Relationship Satisfaction	-.28 (<.0001)				
Disabled Sibling	.22 (.001)				
Step 3		.59	30.09 (<.0001)	.20 (<.0001)	68.11
Gender	.08 (.18, ns)				
Relationship Satisfaction	-.13 (.03)				
Disabled Sibling	.10 (.05)				
Attachment-related anxiety	.49 (<.0001)				

It was clear from the results shown in Tables 3.24 and 3.25 that, when at Step 3, attachment-related anxiety was added to the models, there were highly significant results. There was a reduction in the contribution made by having a disabled sibling, whereby it had, as a unique predictor, considerably reduced in significance in both the HADS anxiety and depression model. Additionally, attachment-related anxiety made a highly significant independent contribution in predicting both the HADS anxiety and depression scores. Therefore, it can be concluded that attachment-related anxiety acts as a significant mediator between anxiety and depression. The further significant findings from these sets of analyses, when all the variables had been entered, significant predictors of HADS anxiety were relationship satisfaction and having a disabled sibling (see Table 3.24). Similarly, significant predictors of HADS depression were age and having a disabled sibling (see Table 3.25).

Table 3.25: Hierarchical regression analysis examining the effects of having a disabled sibling and attachment-related anxiety upon HADS depression

Step and variable	*ß* (p)	R	F (p)	$R^2\Delta$ (p)	F Δ
Step 1		.25	4.71 (.003)	.06 (.003)	
Gender	.12 (.06)				
Relationship Satisfaction	-.18 (.007)				
Age	.09 (.17, ns)				
Step 2		.34	6.93 (<.0001)	.05 (<.0001)	12.80
Gender	.12 (.06, ns)				
Relationship Satisfaction	-.18 (.005)				
Age	.12 (.06, ns)				
Disabled Sibling	.23 (<.0001)				
Step 3		.52	15.69 (<.0001)	.15 (<.0001)	45.14
Gender	.06 (.33, ns)				
Relationship Satisfaction	-.04 (.47, ns)				
Age	.17 (.006)				
Disabled Sibling	.13 (.03)				
Attachment-related anxiety	.44 (<.0001)				

Sobel tests

Figure 3.1 illustrates the regressional effects of having a disabled sibling on attachment-related anxiety and, in turn, how attachment-related anxiety has an effect on anxiety symptom scoring after having controlled for relationship satisfaction. It was seen that the path C′ did not fall to zero after including attachment-related anxiety; therefore, in order to identify if the reduction in beta value is big enough to make a claim for partial mediation a Sobel test was carried out (Preacher & Leonardelli, 2010) using unstandardised beta co-efficient. This indicates that attachment-related anxiety did significantly mediate the relationship between having a disabled sibling and HADS anxiety (Sobel $z = 4.07$, $p < .0001$). The hypothesis was therefore supported for attachment-related anxiety as it showed itself to

be a significant predictor in partially mediating the effects between having a disabled sibling and anxiety symptomatology.

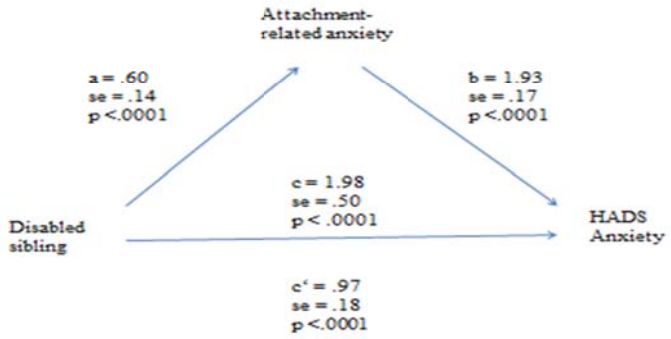

Figure 3.1: Mediation model: Attachment-related anxiety mediating the relationship between having a disabled sibling and HADS anxiety.

Key: (a) = disabled sibling as predictor of mediating variable (MV); (b) = MV as predictor of anxiety [outcome] (c) = total effect path between predictor and outcome ***before*** MV added to model. (c') = total effect path between predictor and outcome ***after*** MV of attachment-related anxiety (c') is added to model.

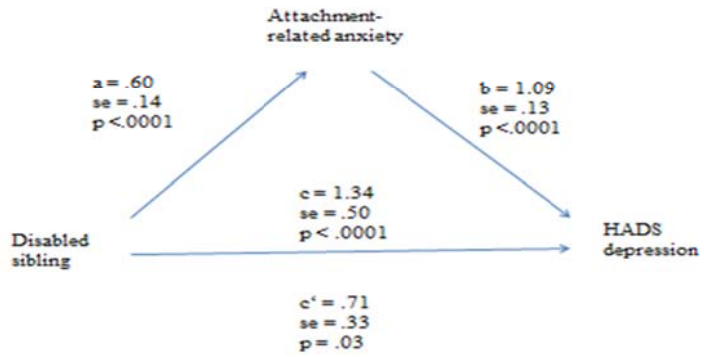

Figure 3.2: Mediation model: Attachment-related anxiety mediating the relationship between having a disabled sibling and HADS depression.

Key: (a) = disabled sibling as predictor of mediating variable (MV); (b) = MV as predictor of depression [outcome] (c) = total effect path between predictor and outcome ***before*** MV added to model. (c') = total effect path between predictor and outcome ***after*** MV of attachment-related anxiety (c') is added to model.

Similarly, Figure 3.2 shows the effects of having a disabled sibling on attachment-related anxiety and, further, how attachment-related anxiety has an effect on depression symptom scoring after having controlled for age. Path C′ did not fall to zero and so a Sobel test was carried out in order to ascertain if partial mediation was present. The Sobel test shows that attachment-related anxiety did significantly mediate the relationship between having a disabled sibling and HADS depression symptomatology (Sobel $z = 3.82$, $p < .0001$). The hypothesis was therefore supported for attachment-related anxiety because it showed itself to be a significant predictor in partially mediating the effects between having a disabled sibling and depression.

3.5.3 Extraversion

Tables 3.26 and 3.27 show the results of the regression analyses when the personality trait of extraversion is added as a last step variable.

Table 3.26: Results of regression analysis of having a disabled sibling and extraversion upon HADS anxiety

		HADS Anxiety			
Step and variable	*ß* (p)	R	F (p)	$R^2\Delta$ (p)	F Δ
Step 1		.30	10.72 (<.0001)	.09 (<.0001)	
Gender	.13 (.05)				
Relationship Satisfaction	-.27 (<.0001)				
Step 2		.39	12.75 (<.0001)	.06 (<.0001)	15.37
Gender	.13 (.04)				
Relationship Satisfaction	-.26 (<.0001)				
Disabled Sibling	.25 (<.0001)				
Step 3		.44	12.99 (<.0001)	.04 (.001)	11.56
Gender	.14 (.02)				
Relationship Satisfaction	-.26 (<.0001)				
Disabled Sibling	.21 (.001)				
Extraversion	-.21 (.001)				

Table 3.27: Results of regression analysis of having a disabled sibling and extraversion upon HADS depression

Step and variable	*ß* (p)	R	F (p)	$R^2\Delta$ (p)	F Δ
Step 1		.23	4.02 (.008)	.05 (.008)	
Gender	.12 (.07, ns)				
Relationship Satisfaction	-.17 (.01)				
Age	.08 (.21, ns)				
Step 2		.34	6.58 (<.0001)	.06 (<.0001)	13.54
Gender	.12 (.06, ns)				
Relationship Satisfaction	-.17 (.009)				
Age	.11 (.10, ns)				
Disabled Sibling	.24 (<.0001)				
Step 3		.47	11.47 (<.0001)	.11 (<.0001)	27.68
Gender	.14 (.03)				
Relationship Satisfaction	-.17 (.007)				
Age	.06 (.30, ns)				
Disabled Sibling	.17 (.009)				
Extraversion	-.33 (<.0001)				

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Tables 3.26 and 3.27 show that the criterion for step four was met; extraversion has a significant negative association with anxiety and depression, even after controlling for having a disabled sibling and the demographic variables. The influence is more pronounced for depression than anxiety. The depression model displays a much larger effect size, both in the overall model and the individual extraversion beta value. The beta size for having a disabled sibling is reduced in both models once extraversion has been added but remains significant. In the anxiety model (see Table 3.26) it appears that having a disabled sibling and lower levels of extraversion are equal predictors of anxiety whereas lower levels of extraversion appears to be a significantly more powerful predictor of depression than having a disabled sibling (see Table 3.27). The ameliorating effect of relationship satisfaction is particularly significant in the anxiety model and is also significant in the depression model. Partial

mediation appears to have taken place but Sobel tests will be carried out in order to ascertain if the reduction in beta size is sufficiently significant to say extraversion is a partial mediator.

Sobel tests

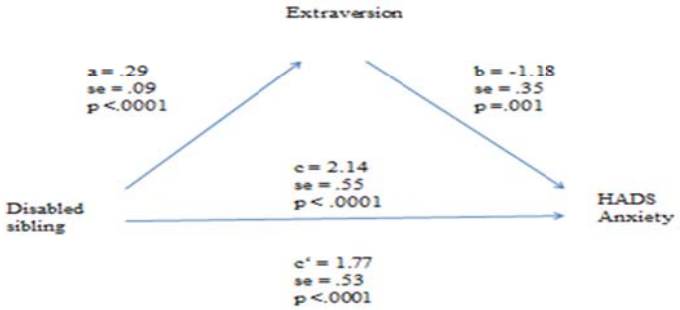

Figure 3.3: Mediation model for extraversion mediating the path between having a disabled sibling and HADS anxiety symptomatology.

Key: (a) = disabled sibling as predictor of mediating variable (MV); (b) = MV as predictor of anxiety [outcome] (c) = total effect path between predictor and outcome ***before*** MV added to model. (c') = total effect path between predictor and outcome ***after*** MV of extraversion(c') is added to model.

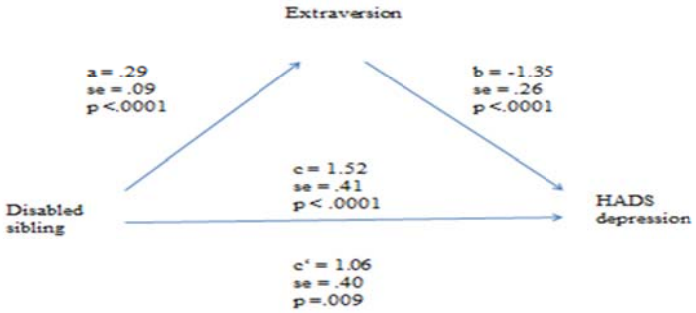

Figure 3.4: Mediation model for extraversion mediating the path between having a disabled sibling and HADS depression symptomatology.

Key: (a) = disabled sibling as predictor of mediating variable (MV); (b) = MV as predictor of depression [outcome] (c) = total effect path between predictor and outcome ***before*** MV added to model. (c') = total effect path between predictor and outcome ***after*** MV of extraversion (c') is added to model.

Sobel tests were carried out (Preacher & Leonardelli, 2010) to test the significance of the indirect effect of extraversion on symptom scoring of HADS anxiety and depression (see Figures 3.3 & 3.4). It was found that extraversion significantly mediated the outcome between having a disabled sibling and HADS anxiety symptomatology (Sobel $z = 2.33$, p = .02). Likewise, it was found that extraversion significantly mediated the outcome between having a disabled sibling and HADS depression symptomatology (Sobel $z = 2.74$, p = .006). This was evident in the reduction in beta values in path c' when extraversion was added as a mediating variable, therefore lower levels of extraversion acted as a partial mediator in explaining why having a disabled sibling can cause anxiety and depression.

3.5.4 Neuroticism

Tables 3.28 and 3.29 show the results of the regression analyses when the personality trait of neuroticism is added as a last step variable.

Table 3.28: Results of regression analysis of having a disabled sibling and neuroticism upon HADS anxiety

Step and variable	*β* (p)	R	F (p)	$R^2\Delta$ (p)	F Δ
Step 1		.31	11.56 (<.0001)	.10 (<.0001)	
Gender	.14 (.04)				
Relationship Satisfaction	-.27 (<.0001)				
Step 2		.39	13.27 (<.0001)	.06 (<.0001)	15.19
Gender	.14 (.03)				
Relationship Satisfaction	-.27 (<.0001)				
Disabled Sibling	.24 (<.0001)				
Step 3		.70	53.88 (<.0001)	.34 (<.0001)	148.95
Gender	.04 (.46, ns)				
Relationship Satisfaction	-.09 (.07, ns)				
Disabled Sibling	.13 (.009)				
Neuroticism	.63 (<.0001)				

Tables 3.28 and 3.29 clearly demonstrate that the criterion for step 4 was also met; the highly significant association between neuroticism and anxiety and depression could be seen. The effect size of neuroticism was larger in the anxiety model; again both in the overall model and the individual beta size. The beta sizes for having a disabled sibling were reduced in both the anxiety and depression models but remained significant; therefore, in both models having a disabled sibling was a strong predictor of anxiety and depression symptomatology but neuroticism was a more significant predictor. It was noted from the demographic variables that age was still a significant predictor for depression.

Table 3.29: Results of regression analysis of having a disabled sibling and neuroticism upon HADS depression

Step and variable	*ß* (p)	R	F (p)	$R^2\Delta$ (p)	F Δ
Step 1		.24	4.27 (.006)	.06 (.006)	
Gender	.12 (.06, ns)				
Relationship Satisfaction	-.18 (.008)				
Age	.02 (.23, ns)				
Step 2		.33	6.73 (<.0001)	.06 (<.0001)	13.34
Gender	.12 (.06, ns)				
Relationship Satisfaction	-.18 (.007)				
Age	.11 (.10, ns)				
Disabled Sibling	.24 (<.0001)				
Step 3		.26	15.33 (<.0001)	.15 (<.0001)	44.30
Gender	.05 (.40, ns)				
Relationship Satisfaction	-.06 (.30, ns)				
Age	.13 (.04)				
Disabled Sibling	.17 (.006)				
Neuroticism	.42 (<.0001)				

Sobel tests

It was found that neuroticism acted as a significant partial mediator in the outcome between having a disabled sibling and both HADS anxiety symptomatology (Sobel $z = 2.92$, $p = .004$) and HADS depression symptomatology (Sobel $z = 2.91$, $p = .004$). This was evident in the reduction in beta values in path c' when neuroticism was added as a mediating variable (see Figures 3.5 and 3.6).

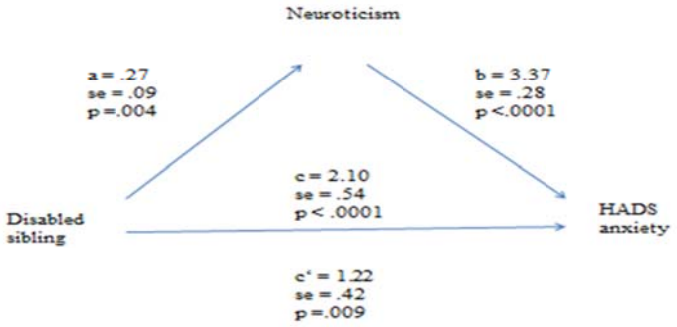

Figure 3.5: Mediation model for neuroticism mediating the path between having a disabled sibling and HADS anxiety symptomatology.

Key for Figures 4.5 and 4.6: (a) = disabled sibling as predictor of mediating variable (MV); (b) = MV as predictor of anxiety [4.5 outcome] or depression [4.6 outcome] (c) = total effect path between predictor and outcome ***before*** MV added to model. (c') = total effect path between predictor and outcome ***after*** MV of neuroticism (c') added to model.

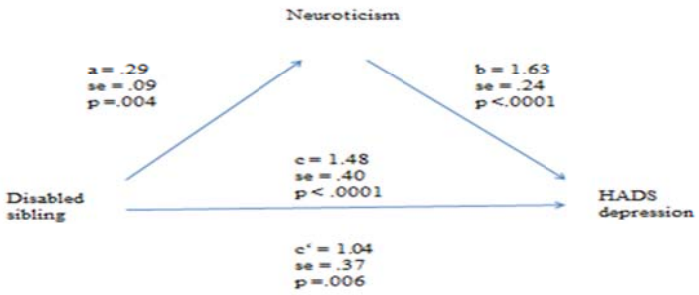

Figure 3.6: Mediation model for neuroticism mediating the path between having a disabled sibling and HADS depression symptomatology.

3.5.5 Openness

Tables 3.30 show the results of the regression analyses when the personality trait of extraversion is added as a last step variable.

Table 3.30: Results of regression analysis of having a disabled sibling and openness upon HADS depression

Step and variable	*ß* (p)	R	F (p)	$R^2\Delta$ (p)	F Δ
Step 1		.21	3.11 (.03)	.04 (.03)	
Gender	.12 (.09, ns)				
Relationship Satisfaction	-.16 (.02)				
Age	.04 (.47, ns)				
Step 2		.32	5.99 (<.0001)	.06 (<.0001)	13.88
Gender	.12 (.18, ns)				
Relationship Satisfaction	-.16 (.02)				
Age	.08 (.24, ns)				
Disabled Sibling	.25 (<.0001)				
Step 3		.35	5.72 (<.0001)	.02 (.04)	4.43
Gender	.09 (.18, ns)				
Relationship Satisfaction	-.16 (.02)				
Age	.08 (.24, ns)				
Disabled Sibling	.27 (<.0001)				
Openness	-.14 (.04)				

Table 3.30 shows that the model was reduced in significance when openness was introduced to the regression model to predict depression. Having a disabled sibling increased in effect size when openness was added and so openness was not expected to be a significant mediator in the relationship between having a disabled sibling and depression. However, higher levels of openness remained a significant unique negative predictor of depression; likewise, higher levels of relationship satisfaction offered a protective effect over depression symptomatology.

Sobel test

A Sobel test found that while high levels of openness showed an ameliorative trend towards depression, it was, however, found to be non-significant (p = 0.11). This was evident in the increase in beta value in path c' when openness was added as a mediating variable (see Figure 3.7).

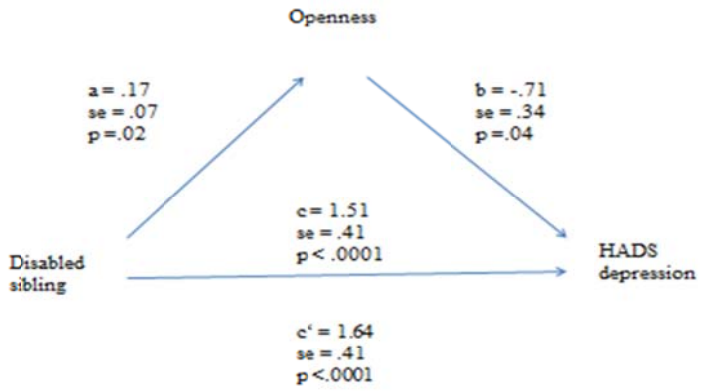

Figure 3.7: Mediation model for openness mediating the path between having a disabled sibling and HADS depression symptomatology.

Key: (a) = disabled sibling as predictor of mediating variable (MV); (b) = MV as predictor of depression [outcome] (c) = total effect path between predictor and outcome ***before*** MV added to model. (c') = total effect path between predictor and outcome ***after*** MV of openness (c') added to model.

3.6 Correlational analyses for perceived inconsistent mothering and main variables

Table 3.31shows some unexpected but interesting results. Despite there being a significant propensity for the SDI group to report significantly higher levels of perceived inconsistent mothering than the control group (F (1,272) = 6.96, p = .009), on further examination, no association could be found for the SDI between perceived inconsistent mothering and the variables of attachment-related anxiety, depression and anxiety symptomatology. In contrast, however, the control group showed results that were entirely

consistent with previous empirical research, with expected associations. Likewise, when examining the personality variables, the same pattern follow. There were extremely low associative, non-significant values for the SDI group, whereas the control group is showing significant associations with perceived inconsistent mothering being associated with neuroticism and negatively associated with extraversion, only openness showed no association with either group.

Table 3.31: Correlation values and p-values for SDI group and control group between perceived inconsistent mothering and HADS affective symptomatology, attachment-related anxiety and personality traits

	SDI Group Perceived inconsistent mothering	SDI N	Control Group Perceived inconsistent mothering	Control N
HADSAnxiety	-.03 (.75)	149	0.31 (< .0001)	150
HADSDepress	.01 (.89)	148	0.27 (.002)	150
AttachAnxiety	.10 (.25)	147	0.20 (.02)	149
Extraversion	.07 (.38)	146	-0.22 (.02)	141
Neuroticism	-.02 (.82)	150	0.38 (< .0001)	144
Openness	-.02 (.84)	146	0.07 (.46)	139

3.7 Different disability types

The demographic variables for the DS, ASD and PWS groups are examined in Table 2.3. Please note that two participants were excluded from this set of analyses because they reported that their sibling had both DS and ASD.

3.7.1 Descriptive statistics for Hospital Anxiety and Depression Scale for the three sibling disability types (and control group), including one-way ANOVA analysis

The main aim of this section was to establish if there were any differences between the groups on the reporting of HADS anxiety and depression symptomatology. Table 3.32 shows that the control group had lower scores on both anxiety and depression than all the disability sibling groups. However, the DS group scores were lower than the ASD and PWS sibling groups for both anxiety and depression. The ASD and PWS group had the same scores for anxiety; however, the ASD group scored higher on depression than the PWS sibling group. The groups were subjected to a one-way ANOVA test and Tukey's HSD post-hoc analysis.

Table 3.32: Means and SD for HADS scores of siblings in the three disability groups and control group

HADS scale	DS group (n = 59)	ASD group (n = 31)	PWS group (n = 26)	Control group (n = 116)	One-way ANOVA
	Mean/SD	Mean/SD	Mean/SD	Mean/SD	
Anxiety	8.12 (4.54)	10.23 (4.45)*	10.23(4.14)*	6.97 (4.06)	F (3,229) = 7.43, p<.0001
Depression	3.73 (2.70)	4.97 (2.85)*	4.73 (3.34)*	3.00 (3.14)	F (3,230) = 4.43, p =.005

Key: *= mean different from control group at p <.05;

HADS = Hospital Anxiety and Depression Scale; SD = standard deviation

The effect for anxiety symptomatology was significant. Depression symptomatology also showed significance between the groups. When Tukey's post hoc analysis was carried out it shows that the control group had significantly lower anxiety reporting than the ASD group (mean difference = 3.26, SE= .87, p =.001) and also the PWS group (mean difference 3.26, SE = .92, p =.003). When the depression symptomatology scores were broken down using Tukey's post hoc analysis it shows that there were specific significant differences between the ASD sibling group who reported significantly higher depression symptomatology than the control group (mean difference 1.81, SE = .62, p =.02); the PWS

sibling group also reported significantly higher depression symptomatology than the control group (mean difference 1.73, SE = .66, p =.05).

There were no significant differences found between the DS group and the control group for either anxiety and /or depression symptomatology.

3.7.2 Different influences of sibling disability types in relation to the combined matched control group

The main aim of this section was to try to establish if there were any overall particular aetiological features that might have had an effect on individuals whose siblings have specific disability types. Initially a one-way ANOVA was carried out between the variables and the control group to see if there were any obvious differences between the specific disability groups and the combined control group; Tukey's post-hoc analysis was then applied.

Table 3.33: Means for perceived inconsistent mothering, attachment-related anxiety, neuroticism and extraversion of siblings in the three disability groups and control group

	DS N = 59	ASD N = 31	PWS N = 26	Control N = 116	One-way ANOVA
	Mean /SD	Mean /SD	Mean /SD	Mean /SD	
IncnMother	2.52 (1.98)	3.21 (2.41)	2.52 (1.92)	2.36 (1.91)	F (3,216) = 1.84, p = 0.14
AttachAnxiety	3.52 (1.23)	3.74 (1.15)*	3.64 (1.47)	3.07 (1.07)	F (3,226) = 4.93, p =0.002
Neuroticism	3.06 (0.93)	3.31 (0.71)	3.17 (0.82)	2.93 (0.77)	F (3,228) = 2.30, p = 0.08
Extraversion	3.25 (0.86)	3.23 (0.75)	3.43 (0.72)	3.52 (0.75)	F (3,222) = 2.10, p = 0.10

Key: SD = standard deviation; DS = Down's syndrome; ASD = autistic spectrum disorder; PWS = Prader-Willi syndrome; IncnMother = perceived inconsistent mothering; AttachAnxiety = attachment-related anxiety; *= mean different from control group at p <.05.

Table 3.33 shows that there was only one significant difference found between the specific sibling disability groups and the control group and this was the effect for attachment-related anxiety. When Tukey's post hoc analysis was carried out it shows that the control

group had significantly lower attachment-related anxiety reporting than the ASD group (mean difference = 0.77, SE= .24, p =.007).

3.7.3 Comparative influences for DS, ASD and PWS sibling disability types in relation to their individually closely matched control groups

Correlational analysis was then carried out for each disability type and compared to their specifically matched control group; this was to try to ascertain whether there were explicit relationships that could help to explain the increased affective symptomatology of the particular groups.

Table 3.34: Correlations examining potential associations with HADS anxiety and HADS depression for the DS sibling group (N = 59) and the control group (N = 59)

	DS-HADS Anxiety	DS-HADS Depression	Control-HADS Anxiety	Control-HADS Depression
Inconsistent mothering	.18 (n.s)	.24 (n.s)	.29 (.04)	.36 (.01)
Attach-related anxiety	.68 (<.0001)	.51 (<.0001)	.59 (<.0001)	.73 (<.0001)
Neuroticism	.77 (<.0001)	.47 (<.0001)	.70 (<.0001)	.58 (<.0001)
Extraversion	-.14 (n.s.)	-.24 (n.s.)	-.23 (n.s)	-.41 (.001)

Key: DS = Down syndrome; n.s. = Non-Significant

Table 3.34 shows similar patterns between the DS siblings and their closely-matched control group. Both attachment-related anxiety and neuroticism were significantly associated with HADS anxiety and depression for both groups. As expected, there was no association between the DS sibling group and perceived inconsistent mothering whereas the control group shows an association between perceived inconsistent mothering, anxiety and depression. Extraversion had a negative association with depression for the control group.

Table 3.35: Correlations examining potential associations with HADS anxiety and HADS depression for the ASD sibling group (N = 31) and the control group (N = 31)

	ASD-HADS Anxiety	ASD-HADS Depression	Control-HADS Anxiety	Control-HADS Depression
Inconsistent mothering	.39 (.03)	.14 (n.s)	.39 (.04)	.13 (n.s.)
Attach-related anxiety	.48 (.008)	.46 (.009)	.53 (.003)	.08 (n.s.)
Neuroticism	.54 (.002)	.57 (.001)	.74 (<.0001)	.40 (.03)
Extraversion	-.19 (n.s.)	-.44 (.02)	-.24 (n.s)	-.23 (n.s.)

Key: ASD= Autistic Spectrum Disorder; n.s. = Non-Significant

Table 3.35 shows similar associations between the ASD sibling group and the control group between HADS anxiety and depression and neuroticism and attachment-related anxiety. However, there was no association between attachment-related anxiety and depression for the control group. Interestingly it was noted that ASD siblings had significant associations between perceived inconsistent mothering and HADS anxiety; this pattern followed for the control group. The ASD sibling group also reported low extraversion levels that were significantly associated with HADS depression.

Table 3.36: Correlations examining potential associations with HADS anxiety and HADS depression for the PWS sibling group (N = 26) and the control group (N = 26)

	PWS-HADS Anxiety	PWS-HADS Depression	Control-HADS Anxiety	Control-HADS Depression
Inconsistent mothering	.04 (.86)	-.04 (.86)	.38 (.08)	.13 (.56)
Attach-related anxiety	.56 (.003)	.12 (.56)	.65 (<.0001)	.64 (<.0001)
Neuroticism	.77 (<.0001)	.38 (.05)	.71 (<.0001)	.62 (.001)
Extraversion	-.12 (.56.)	-.37 (.02)	-.27 (.19)	-.51 (.009)

Key: PWS = Prader-Willi syndrome; n.s. = Non-Significant

Table 3.36 shows similar results to the DS and ASD siblings and control groups in that for the PWS sibling and their control group, attachment-related anxiety and neuroticism were highly associated with HADS anxiety and depression; with the exception of attachment-related anxiety and HADS depression for the PWS sibling group. There were no associations with perceived mothering variables for the PWS group but there was a significant relationship between perceived inconsistent mothering and HADS anxiety for their control group. However, again there was a negative association with extraversion and HADS depression for the PWS sibling group and also for their control group.

3.8 Birth Order

As reported in Tables 3.14 and 3.15 younger siblings were significantly more likely to report anxiety and depression symptomatology than older siblings of a disabled individual. One-way ANOVAs showed there was a trend indicated for younger siblings to report higher levels of adult attachment-related anxiety ($F(1,144) = 2.71$, $p = .10$); however, this did not reach significance. When examining the categorical adult attachment styles through independent samples McNemar tests of proportion, the only significant difference shown was that who were older siblings were significantly more likely to be securely attached χ ($N = 146$), $p = 0.005$. There was no difference between being older and younger for fearful attachment ($p = 0.63$), preoccupied attachment ($p = 0.52$) or dismissive attachment ($p = 0.40$). One-way ANOVA tests further showed the non-significant results for extraversion as $F(1,143) = 0.24$, $p = 0.63$, for neuroticism as $F(1,147) = 1.46$, $p = 0.78$ and for openness as $F(1,143) = 0.08$, $p = 0.78$.

Siblings of individuals with DS, ASD and PWS were examined to ascertain if anxiety or depression symptomatology were dependent upon whether the sibling was older or younger than their disabled brother or sister for these specific groups. Older siblings were scored as 1 and younger siblings were scored as 0.

Table 3.37: Mean levels and independent One-way ANOVAs showing differences in younger and older sibling's anxiety and depression symptomatology

	N	Anxiety Mean /SD	Depression Mean /SD	One-way ANOVA HADS Anxiety	One-way ANOVA HADS Depression
DS younger	27	9.19 (4.66)	4.11 (3.13)	F(1,58) =4.06, p=0.05	F(1,58) =0.15, p=0.70
DS older	34	7.23 (4.28)	3.62 (2.46)		
ASD younger	12	11.83 (5.02)	5.25 (3.17)	F(1,28) =4.43, p=0.04	F(1,29) =0.40, p=0.53
ASD older	20	8.68 (3.83)	4.35 (2.80)		
PWS younger	12	9.25 (2.90)	6.50 (3.85)	F(1,24) =1.26, p=0.27	F(1,24) =8.00, p=0.009
PWS older	14	11.07 (4.92)	3.21 (1.89)		

Table 3.37 shows that younger siblings from the ASD and DS sibling groups reported significantly higher anxiety symptomatology than siblings who were born before the disabled sibling. The younger siblings of ASD and DS siblings also reported higher levels of depression but this did not reach significance. This pattern followed through for younger PWS siblings and depression; however, this difference did reach significance. However, in contrast to DS and ASD siblings, the younger PWS siblings reported lower mean levels of anxiety than their older siblings but this did not reach significance.

Chapter 4

Discussion

4.1 Introduction

One of the findings of the study that must be highlighted is that the majority of both SDI and control group participants do not report heightened anxiety and /or depression symptomatology. Similarly, the majority of participants report secure attachment and warm parenting styles. Likewise, the personality trait that scores the highest rating for both groups is agreeableness, and thereafter the reporting of the level of the personality traits is all in an adaptive order, with the lowest scorings then being on neuroticism for both groups. However, it should also be noted that when examined more closely that the SDI are much more likely to report significantly higher levels of anxiety and depression symptomatology than the control group, alongside higher levels of attachment-related anxiety, inconsistent mothering, extraversion and higher levels of neuroticism.

In the initial section of the Discussion, I will discuss potential reasons for the findings of the study, thereafter I will evaluate the validity of the study, while considering the issues of bias, measurement reliability and validity. In the second part of this Discussion I will examine the perceived strengths and weaknesses of the study. Finally, suggested directions for future research will be discussed.

4.2 Anxiety and depression

The first hypothesis of the study, that adult siblings of individuals with disabilities would report higher rates of anxiety and depression symptomatology than those without disabled siblings, was supported. It should be noted that the effect size for reporting anxiety symptoms in the SDI were higher than for the effects of depression, which supports other research (e.g., Norberg et al. 2008). There was also support for the co-morbidity of anxiety and depression for both groups; this can significantly increase the negative effects of these internalising disorders (Norberg et al. 2008; Roy-Byrne et al. 2008).

The findings from the present study supported the research by Piven et al (1990), who found that siblings of autistic individuals scored highly on depression symptomatology

compared to epidemiological studies. However, the overall mean score for depression was still low and so, as previously stated, the majority of participants did not suffer from depressive symptoms. This offers support to Glenn et al. (2009) who found that the majority of families with a disabled child managed well. It also supported Gass, Jenkins & Dunn (2007), who proposed that the majority of siblings who experience stressful events do not necessarily suffer from affective disorders when they are older. However, it was still necessary to further investigate the reasons as to why the adult SDI were at an increased risk of increased anxiety and /or depression in comparison to the control group.

The increased reporting of anxiety and depression in the present study supports the findings of Rossiter and Sharpe's (1991) meta-analytical report on siblings of disabled children, which found that the SDI are at a small but significantly increased risk of developing affective disorders. The present study also supports the suggestion from Rosenman and Rodgers (2006) that stressful events in childhood could lead to a lifelong vulnerability towards affective clinical conditions. Findings suggest that events that were experienced as potentially stressful by the SDI appear to have had a long-term impact and it would be useful if these potential risk factors could be isolated in order to ascertain if they are treatable, thereby improving the affective well-being of the SDI.

Stressful life events may be a contributory cause in the potential aetiology of generalised anxiety and major depression disorders (Hettema, 2008). Given that the two groups in the present study were very closely matched and that the primary differentiating variable of the group that scored significantly higher on anxiety and depression symptomatology was having a disabled sibling; a tentative conclusion can be drawn whereby elements of having a disabled sibling were perceived as stressful and has contributed towards long term vulnerabilities in anxiety and depression (Rosenman & Rogers, 2006). Previous research has indicated a causal link between stressful situations and the onset of anxiety and depression disorders (Kendler et al. 2004; Spinhoven et al. 2010). Spinhoven et al (2010) suggested that stressful events in childhood could be a greater indicator of affective disorders than lifespan negative episodes. It should be remembered that siblings of disabled individuals will potentially experience both types of these stressful events; with additional daily pressures arising through growing up with a disabled sibling with the possible combination of specific negative life episodes, such as hospitalisation of their sibling, behavioural episodes from their sibling and possible negative interactions with their parents resulting from the additional

pressures of looking after a disabled child (McHale & Gamble, 1989). These events could continue indefinitely.

Adverse events in childhood can be one of the triggers for the onset of anxiety and depression and these events can lead to lifetime vulnerability towards affective disorders. Emotional neglect from parents has been specifically mentioned as one of the contributory risk factors in the onset of anxiety and depression (Spinhoven et al. 2010). If this was a contributory factor, speculatively, it might be that the sibling group was not deliberately neglected by their parents, however, it might be that their parents had to spend so much of their time dealing with the disabled sibling that they had exhausted their emotional resources to deal in an emotionally appropriate and resourceful way with their children without disabilities; thus the child without disabilities could feel emotionally neglected. Conversely, it might have been that the sibling group compared the attention the disabled sibling was getting with the amount of attention they perceived they were receiving and found their own emotional care to be lacking as a result, which might have paved the way for the development of anxiety and depression disorders. If the latter suggestion has any validity it would offer support to Allen & Rapee's (2009) proposition that it might be that once children have experienced negative life events they would consequently be more prone to affective disorders. Possibly it was the way that they perceived events happening around them as being more negative as opposed to the negative events actually being directed at them. If the siblings' emotional reaction to the perceived negative event of disparity of parental care left them demoralised, it might have made them more vulnerable to the harmful cyclical affective effect suggested by Allen and Rapee.

In a similar vein, it has been suggested that parental stress is influential in the developmental maladjustment in the SDI and it has been proposed that good family communication and routines might alleviate some of these problems (Dodd, 2004; Giallo & Gavidia- Payne, 2006; Spinhoven et al. 2010). It has also been suggested that additional caretaking responsibilities for the disabled sibling might explain elevated rates of affective problems. Eisenberg et al. (1998) also found lower levels of 'expressiveness' in the SDI in comparison to the control group, and considered this to be problematic as the siblings reported feeling more inhibited about discussing their own problems when they perceived the parents to be more concerned about the welfare of the disabled sibling. SDI were further concerned about any future caretaking responsibilities that they may have and the lack of familial communication regarding this. They felt parents would withhold information from

them regarding their fears, anxieties and ideas in respect of their disabled siblings and the expectations that they had for them regarding their future sibling role (Dodd, 2004; Eisenberg et al. 1998; Giallo & Gavidia- Payne, 2006). This is re-iterated by the findings of Heller and Kramer (2009) who found that siblings are rarely involved, until the parents are quite elderly, in the planning of their disabled sibling's future. It was indicated that the reasons for this might be understandable in that the parents did not want to place any weight of responsibility upon their children, however, it was suggested that the siblings do wish to part of the process, regardless of the level of support they intend to offer their disabled sibling. Not knowing the level of involvement they might have in their disabled siblings lives might subliminally prevent the SDI from making extensive plans of their own, which could act as a potential stressor for them. These are all potential factors that could help to explain the heightened propensity of the SDI group towards affective disorders and they deserve further exploration. Specific potential factors that might contribute towards the SDI's increased propensity will now be examined.

4.3 Demographic factors

4.3.1 Gender

The research hypothesis regarding gender was supported, whereby a significantly higher effect was found in females reporting higher levels of anxiety and depression than the males within both groups. Interestingly though, the males from the SDI group reported a trend towards higher levels of depression symptomatology than control group males and higher levels of depression and similar levels of anxiety to the control group females, though this was not significant. The second research hypothesis regarding gender, was, however, not supported as there was no interactive effect between the gender of the participant and having a disabled sibling upon anxiety and depression. Put simply, the above results showed that the correlations between having a disabled sibling and anxiety and depression held equally across men and women.

However, the present research found females from the SDI group to have a significantly higher propensity towards higher anxiety symptomatology than males from their group and that the females from the control group had a higher propensity, albeit not significant, to report higher anxiety and depression scoring than males from their group; these

findings support past research (Nolen-Hoeksema, 2001; Parker & Hadzi-Pavlovic, 2001; WHO, 2010). The females from the control group also offered tentative support for Parker and Hadzi-Pavlovic's (2001) suggestion that there is no general female propensity towards depression but it is more often reported due to the higher rates of female anxiety. The results could also be explained by the suggestion that females spend more time reflecting on interpersonal matters than males and this could lead to negative emotionality (Wilhelm et al. 2002).

The findings of heightened female anxiety and depression in the SDI group might be due to the extra responsibilities that were often placed upon sisters as children, particularly the older ones, of disabled siblings (Stoneman et al. 1988), which might have limited the amount of time that they had for socializing outside the home, which can be an important ameliorating effect against anxiety and depression build-up (Crnic et al. 1983). This finding might be tempered by the suggestion that females in typically functioning households generally have more caretaking tasks to do (McHale & Gamble, 1989; Noller, 2005); the increased rates of anxiety and depression within the SDI cohort might indicate that they had much more than normal amounts of caregiving to do. These suggestions are, however, speculative and more investigation needs to be done to draw firmer conclusions.

While it did not reach significance, the prevalence of SDI males who reported higher levels of depression symptomatology than the comparison males and higher levels of depression and similar levels of anxiety symptomatology in comparison to females from the control group was an interesting finding. It was not clear whether this was an affective pattern, residual from childhood experiences or if it is a current phenomenon; further research into high levels of male SDI affective symptomatology in comparison to the general population should be carried out.

4.3.2 Age

The first hypothesis regarding age was partially supported, whereby older individuals from the control group reported less depression symptomatology than younger participants; however, the hypothesis was not supported for the SDI group because there was no disparity in depression symptomatology with age. The second hypothesis was supported because there was no association with age and anxiety symptomatology. The third hypothesis was not

supported as there was no evidence of age playing a moderating effect between having a disabled sibling and anxiety or depression.

Interestingly, there was no association between the aging process, having a disabled sibling and depression. Previous research had reported that children with disabled brothers or sisters had a tendency to report increased depression symptomatology (Ross & Cuskelly, 2007; Rossiter & Sharpe, 2001); however, the results here indicate that, despite initial earlier symptomatology, the effects of having a disabled sibling do not compound themselves and become more significant with age. It was hoped that this study might give support to Sellinger et al's (2006) finding that PWS individuals calmed down with age and therefore would alleviate affective problems in the SDI, and overall age does seem to be a factor associated with decreased depression symptoms in older SDI.

The trend towards reduced anxiety reporting in the present research offers tentative support to previous studies, where age reduces anxiety symptomatology (Alexopoulos et al. 1995; Byers et al. 2010; Henderson et al. 1998). Henderson and colleagues (1998) attributed this decline in symptoms to the reduction of risk factors, for example, the effects of parental separation or divorce should have eased and people often become more financially stable as they become older.

4.3.3 Relationship satisfaction

The first hypothesis regarding relationship satisfaction was supported with participants reporting higher levels of relationship satisfaction and lower levels of anxiety and depression symptomatology for both groups. The second hypothesis was not supported because the SDI group actually experienced less parental divorce than the control group; albeit this difference was not significant. Furthermore, there was no association for either group between parental divorce and anxiety and depression; parental contact after the divorce did however lessen anxiety and depression symptoms for the control group but there was no association for the SDI group. However, the findings of high relationship satisfaction offering an ameliorating effect against anxiety and depression did not remain constant when looking at the interaction effect of having a disabled sibling and relationship satisfaction. In other words, the correlational effect between having a disabled sibling and anxiety and

depression remains the same despite high levels of relationship satisfaction; therefore, the third hypothesis was not supported.

The positive effect of relationship satisfaction supports many other findings (Amato & Cheadle, 2005; Collins et al. 2002; Cooper, 2002; Davis, Morris & Kraus, 1998). For example, Amato and Cheadle (2005) proposed marital satisfaction to be an important factor in emotional well-being, whereas Bulloch et al (2009) suggested relationship dissolution to be an important factor in the development and maintenance of anxiety and depression. They further emphasised that pre-existing high levels of anxiety and /or depression might be a contributory factor in pre-disposing people to a higher likelihood of relationship breakdown, thereby adding a cyclical effect. It is interesting that whilst the SDI group reported higher levels of anxiety and depression symptomatology, it appeared not to lead to higher levels of marital breakdown and discontent within the SDI relationships. Furthermore, when marital breakdown did occur in this cohort there was no significant association with anxiety and /or depression for either group; this did not support the majority of other research (Bulloch et al. 2009). It did, however, support the lack of moderating effect of relationship satisfaction between having a disabled sibling, anxiety and depression found in the present research.

Interestingly, the mean scores for the SDI reported them as being in relationships for longer and experiencing higher levels of relationship satisfaction than the control group. A potential reason for is that the SDI might feel that they had the primary position in their partner's life, whereby they received sufficient attention and were no longer having to play 'second best' to their disabled sibling; possibly if they were secure in the knowledge that they were cared for, entirely for their own sake, this might have offered a protective effect against anxiety. This area of social support, whilst renowned for alleviating anxiety and depression (e.g., Amato & Cheadle, 2005), might be especially valid amongst siblings who have grown up with disabled brothers and sisters and would benefit from further exploration.

Additionally, the descriptive statistics showed that contrary to the anecdotal claims whereby parents of disabled children experienced divorce rates of up to 80% (Richardson, 2008), the present study found a parental divorce rate which was marginally lower than that of the control group. Interestingly, parental divorce made no significant impact in predicting anxiety or depression symptomatology as adults for either group. Speculatively, this variable was expected to have significantly increased the affective reporting for the SDI group because it was considered if one parent left the familial home then the increased demands of

looking after the disabled sibling would fall to the parent who was left, who would then potentially not have sufficient time for the children without disabilities; additionally it was further speculated that increased caregiving requests for help in looking after the disabled child would be made to the SDI.

Additional caregiving responsibilities have been found to be conducive to the development and maintenance of anxiety and depression in siblings of the disabled (Gold, 1993; McHale & Gamble, 1989; Naylor & Prescott, 2004). Further, parental divorce might have meant the absence of a parent who had been regarded as a significant source of support and who would now no longer be available on a daily basis. If the sibling was already perceived to be in a stressful situation, the lack of availability of the parent could potentially exacerbate any underlying vulnerability towards affective disorders (Amato & Cheadle, 2005). However, these scenarios were unfounded within this cohort but it may be that they are areas worthy of further investigation.

4.3.4 Socio-economic status

The first hypothesis regarding socio-economic status which looked for an effect on the relationship between socio-economic status, anxiety and depression was not supported in this study for the SDI group; however, a small effect was found those in the lower socio-economic bands and depression symptomatology for the control group. Likewise, the second research question, which tested if socio-economic status moderated the relationship between having a disabled sibling and anxiety and depression, was also not supported.

The lack of interaction or moderating effect of higher levels of socio-economic status on the correlation between anxiety and /or depression and having a disabled sibling was an interesting finding because, according to previous research, lower socio-economic status accounts for increased rates of affective disorders and applies to all ages (Anli & Karsli, 2010; Butterworth et al. 2009) and higher levels might offer a protective effect from adjustment disorders (Hastings, 2003b).

The mean scores for employment type and income in this study were slightly higher (but non-significant) for the SDI group as compared to the control group, which might have helped to explain the results found here as their slightly higher earnings might produce an ameliorating effect against anxiety and depression. The effects of financial downturn,

possibly due to the mother not having the employment opportunities she might otherwise have had (Banks et al. 2001) might have influenced the childhood homes with disabled children (Eisenhower & Blacher, 2006; Emerson et al. 2006). This might have caused a propensity towards anxiety and depression, but as adults they can now run their careers and finances independently and rise through the SES scales, which could account for the non-significant results found here.

4.3.5 Educational attainment

The first hypothesis of educational attainment on anxiety and / or depression symptomatology, found a clear effect for the control group in alleviating depression symptoms but no effect was found for the SDI group. The second question, which tested if educational attainment levels moderated the relationship between having a disabled sibling and anxiety and /or depression, was unsupported in this study. While the present study found significantly higher educational levels for the SDI group, no significant moderating effect was found; thereby indicating that the correlation between having a disabled sibling and anxiety and depression remains constant even when higher educational levels have been achieved.

Previous research has shown that increased educational levels have been reported to potentially offer an accumulative lifelong protective effect against anxiety and depression (Bjelland et al. 2008; Gale et al. 2009). This suggested that the results the present SDI cohort scored for anxiety and depression symptomatology might be conservative when applied to other SDI without high education levels. An explanation for the elevated education levels in this cohort might be that the sibling group represented here are self-selected and recruited through disability or sibling charities. The significant discrepancy in educational levels could be explained by the fact that it is often people who are brighter that will access these places of support (Hastings, 2003b). However, it could also be argued that they might have sought out these places of help because they were already suffering from symptoms of anxiety and /or depression and needed support.

The parental levels of education were also significantly higher for the SDI group than the control group but again there was no association between the SDI group and anxiety and depression. The father's educational level has been found to be particularly important in

enabling general family adjustment (Trute, 1990). Past research has also indicated that increased parental education levels might offer an ameliorating influence upon anxiety and depression because they would be more likely to offer their children without disabilities access to different intervention programmes (Hastings, 2003) and these increased educational levels would perhaps enable them to react more flexibly to the situation regarding their disabled child through finding different coping mechanisms (Gale et al. 2009; Hastings, 2003b). SDI parental educational levels could prove to be a very interesting avenue for future exploration in helping to explain SDI affective outcomes.

4.3.6 Demographic variables exclusive to the SDI

The hypothesis was partially supported where poorer prognosis was predictive of anxiety and interestingly less severe disabilities and being the primary carer were predictive of depression. Higher levels of paternal adjustment had an ameliorating effect upon depression and that the sibling younger than the disabled individual was more likely to predict both anxiety and depression.

Interestingly, there was no association between the severity of the disability and anxiety but counter-intuitively, the less severe a disability was the more predictive of depression it was. This was in contrast to the proposal that an important factor in the development and maintenance of affective disorders might be due to the severity of the disability (Rossiter & Sharpe, 2001). Hastings (2003b) also found that the more severe the disability, the less likely the sibling was to benefit from intervention programmes. Dodd (2004) however suggested that the degree of disability did not significantly affect the siblings but she did recognise that it has a wide impact on family life. This is supported by Heller and Kramer (2009) who found no association with the severity of the disability and the expectation of the SDI to offer future caregiving to their disabled sibling. The present study goes in the same direction regarding severity of the disability as it could find no significant effect for any of the established scales when the severity of the disability was measured against them, consequently suggesting that perversely if the disability is particularly severe this is not a particularly important factor when related to the SDI responses towards their siblings. The conclusions drawn by Meadan et al (2010) suggest that presently the type of support or intervention that will best help the SDI is not really known and they recommend actually asking the siblings for the best way forward, in terms of supporting their adjustment.

The authors also noted that the sibling is a member of the wider family and that the family system theory indicates that by supporting the SDI there will hopefully be an ameliorating effect on the whole family (Meadan et al. 2010).

Speculatively, however, it might be that the impact of the severity of the disability was an important feature when the SDI was younger and still living at home, perhaps with caregiving tasks to attend to but it becomes less important as the sibling without disabilities becomes older and possibly moves away from the family home and is therefore less disturbed by the day to day activities. Or, possibly, as an adult, the SDI might find it distressing to witness their less severely disabled sibling struggling to fit in to mainstream society through recognising that they are somehow 'different' to others and not fully fitting in, which might explain increased depression symptomatology in the sibling. This would be in possible contrast to those who are more severely disabled being unaware that they are 'different' to others and consequently carrying on feeling loved and cared for as they always have, which might be a comfort to the SDI. These are important points and further research into adult SDI affective reactions to the severity of the disability would be worthwhile.

A significant relationship between raised anxiety symptomatology and a poor prognosis for their disabled sibling was found, which supports the findings of Rossiter and Sharpe (2001). Speculatively, on a brotherly or sisterly level, they were probably anxious about the outcome for their disabled sibling and any emotional or physical discomfort the sibling was experiencing. Or, indeed, the consequences of a poor prognosis for their disabled sibling might result in, on a day-to-day level, the SDI having to access different authorities, such as health and social. Consequent frustrations, such as waiting for appointments, delays in being seen by a professional, appointments being cancelled, lack of facilities and bureaucracy all of which are time consuming in already busy lives and will possibly give rise to feelings of anxiety.

In partial support of Eisenberg et al's (1998) findings, my study also found that where the disabled sibling resided made no difference to the affective state of the sibling; this was unless the sibling was the primary carer for their disabled sibling, which was predictive of depression symptomatology. This expanded upon previous research where it was found that extra caregiving responsibilities in childhood were associated with elevated rates of anxiety and depression (Crnic et al.1983; Cuskelly, Chant & Hayes, 1998; McHale & Gamble, 1989; Rossiter & Sharpe, 2001; Stoneman et al. 1988). The slightly increased prevalence towards

depression symptomatology was perhaps unsurprising given the propensity of parents of the disabled, most often the mothers who are usually the primary carers, to suffer from anxiety and depression (Rossiter & Sharpe, 2001). It would follow that the pressures and worries that the sibling who has undertaken to care for their disabled sibling should have a tendency to follow the same affective path as the parent. This area should be one of primary concern due to more individuals with disabilities living for longer, aging parents may become less capable of dealing day to day with the responsibilities of the individual with disabilities and consequently the SDI may feel the obligation to take on the responsibility of their sibling (Hodapp & Urbano, 2007).

This is also in light of increased government cutbacks in areas of social welfare, which include a reduction in access to state benefits and also access to day care services and respite centres (Mencap, 2008). This situation might indeed worsen over time as more individuals with disabilities survive into adulthood and increasing pressure will be put onto the welfare systems (Hodapp & Urbano, 2007).

However, it was very important to assess the reasons behind the sibling assuming primary care and if this was through their own choice or through overt or subliminal pressure or expectation applied by the family, or indeed the welfare services. Speculatively, it was assumed that if it was the sibling's sole decision then they must have been aware of most of the issues that would arise in day to day living and be prepared to adjust for these. However, if the sibling felt emotionally coerced into being the primary carer, this could potentially lead to quite deep-rooted affective disorders. The respondents in this study who were the primary carers all reported their siblings as having quite mild disabilities but they still suffered from an elevated rate of anxiety and depression symptomatology; future research should closely examine amongst sibling primary carers, the severity of the disability, the reasoning behind becoming the primary carer, the amount and type of support that is received from the family, friends and the authorities and the rate of anxiety and depression within these individuals.

Finally, my finding that well-adjusted parents, who are perceived as accepting their child's disability, had a protective influence on the SDI group in that they were less likely to report anxiety or depression symptomatology. This finding also supports previous research (Giallo & Gavidia-Payne, 2006; Moore et al. 2002). A study on the long-term effects of autism further emphasised that parental social support towards the sibling without disabilities is important throughout life; they suggested that this might improve the relationship quality

between the siblings (Seltzer et al. 2009), which could further alleviate affective stress. It has been found in childhood that a positive parental approach to their child with disabilities was the best predictor of the sibling accepting his brother or sister with disabilities (Gold, 1993; Powell & Gallagher, 1993) and was also associated with increased adjustment in the sibling (Dodd, 2004; Powell & Gallagher, 1993). It would seem, in the present study, that the positive paternal adjustment reported by the SDI cohort did have an alleviating effect on the long-term outcome of depression symptomatology, however, it must be noted that this was a cross-sectional study and longitudinal research will be necessary to establish the exact causes for this.

4.4 The effects upon the SDI of perceived inconsistent mothering

As previously noted the majority of participants from both groups perceived that both their mothers and fathers offered a warm parenting style; however, there was a significant propensity of more participants from the SDI group to report higher levels of perceived inconsistent parenting, particularly mothering. This supported the first research hypothesis. The second research hypothesis yielded some very interesting results, whereby there was almost no association between the SDI perception of inconsistent mothering and the variables of HADS anxiety and depression symptomatology, attachment-related anxiety, neuroticism or extraversion. This was unexpected and contrary to previous research. However, the results for the control group went in exactly the expected direction with strongly significant associations between all the variables. The third hypothesis of the mediation effect of perceived inconsistent mothering between having a disabled sibling and anxiety or depression was not supported. This indicated that despite the higher levels of perceived inconsistent mothering within the SDI, this parenting style did not explain why there are raised levels of anxiety and depression within the sibling group.

Research to date has indicated fairly consistent findings that parenting in the early years is one of the most significant influences on a child's environment (Bowlby, 1973, 1980; Gallagher & Cartwright-Hatton, 2008) and that early childhood adversity can lead to a higher manifestation of clinical affective problems (Mikulincer & Shaver, 2007; Moskvina et al. 2007; Rosenman & Rodgers, 2006). The SDI group possibly faced additional stressors to the norm in childhood (Giallo & Gavidia-Payne, 2006; Moore et al. 2002; Rossiter & Sharpe, 2001), and as parenting styles play such a significant part in childhood development

(Chorpita & Barlow, 1998), it is thought that they would have a significant effect on the development of SDI attachment styles and personality traits. However, while the control group appear to follow the above pattern and supported the previous research regarding the associations with inconsistent mothering, attachment-related anxiety (Cassidy et al. 2009), heightened neuroticism, lowered levels of extraversion and affective symptomatology (Moskvina et al, 2007 Rosenman & Rodgers, 2006, Watson et al. 2005); the SDI group went in the opposite direction and show no associations. Therefore, despite the highly significant mediating effects of attachment-related anxiety, neuroticism and extraversion on anxiety and depression symptomatology for the SDI, it appears that inconsistent mothering is isolated from having any residual effect within the SDI. This is an area that requires much further investigation.

The present findings where there was a higher rate of reporting of inconsistent parenting is not surprising as intuitively it would be expected that the parent could not direct all the attention towards the SDI whenever attention was required, particularly if the sibling with disabilities was engaged in either medical or behavioural issues at the time consequently requiring immediate and often prolonged parental attention (McHale & Gamble, 1989; Moore et al. 2002; Rossiter & Sharpe, 2001). What is surprising, when considering the scenario of the time and care potentially necessarily being diverted from the siblings without disabilities as one of perhaps the inevitable consequences of having a disabled sibling (Hauenstein, 1990), is that it would be expected to have had an adverse reaction to the parents within the SDI.

Speculatively, a potential reason for the sibling group to report more inconsistent parenting is that the SDI might have perceived that they had to be available to receive attention in-between the parental care-giving responsibilities to the disabled child. The SDI might have perceived this as ill-timed and intrusive; further, the parental responses to the SDI might have been exaggerated and inappropriate due to lack of time. Consequently, the perception that the parents had a tendency to put their own needs ahead of the SDI might have arisen, resulting in the development of ambivalent attachment strategies within the SDI (Ainsworth et al. 1978; Rholes et al. 1998). However, I suggest that it may be that the adult cognitive response has overridden the normative association between inconsistent mothering and attachment-related anxiety. This could be due to a process of rationalisation, where the adult SDI realised that perhaps with the on-going demands placed upon the parent by the disabled sibling, the parent had little option other than to respond in the way he or she did.

A further suggestion for increased reporting of inconsistent mothering might be that the mothers were overprotective in their style of parenting (Heinonen et al. 2004; Hinnen et al. 2009; Kaitz & Maytal, 2005). Whilst Hinnen et al (2009) found no indication that adult reporting of parental overprotection was significantly associated with attachment-related anxiety within a normal population, it might be that within the SDI the parents had an exaggerated fear that something adverse could happen to their well child, which would be outside of their coping resources. Consequently, their natural response might have been to ensure that nothing untoward happened to the child they perceived as healthy, which resulted in over-protective behaviour. The child might then have become anxious and confused over the potential vacillating behaviour of the parent, as on the one hand the child might have perceived a form of parental neglect as the parent could not devote the time the child desired. However, conversely the parental over-protection could also have been perceived by the SDI as controlling, smothering and inappropriate. These factors could help to explain why the SDI perceived more inconsistent parenting than the control group but as these are regarded as conditions for the development of attachment-related anxiety (Carnelly et al. 1994, Nakash-Eisokovits et al. 2002) it was interesting that no association was made between the increased reporting of inconsistent mothering and the increased reporting of attachment-related anxiety by the SDI.

Conversely, it might have been that the parents with a disabled child were overly demanding of their child without disabilities (Moore et al. 2002; Powell & Gallagher, 1993); so that in some way, the child without disabilities could somehow ‘compensate’ for their child with disabilities. This was a speculative reason but one that could explain the reporting of inconsistent mothering and the development of attachment-related anxiety and is therefore an area worthy of further investigation.

The study by Rosenman and Rodgers (2006) is a similar design to my study and yielded similar results, where they examine a large, but randomly selected, adult cohort and ask retrospective questions regarding adversities in childhood up to the age of 16. The authors specifically found highly significant associations between remembered childhood adversity and high levels of neuroticism; however, unlike my study, there is no effect on extraversion. However, Rosenman and Rodgers also found that the effects of maternal depression have lasting and fundamental consequences that do not subside with age. The authors further suggest that the negative affect process is then influential in subsequent life experiences and that this affects both genders equally. This is why it is surprising that my

study found no association between inconsistent mothering, personality traits and affective symptomatology for the SDI. Maternal depression is not, however, examined in my study but would be an interesting factor for future research because maternal depression appears to be considerably more prevalent in mothers of disabled children than those with normal functioning children (Baker, Seltzer & Greenberg, 2011; Motamedi, Seyednour, Noorikhajavi & Afghah, 2007). However, due to the non-associative findings of my study, between perceived inconsistent mothering, having a disabled sibling, increased levels of neuroticism, lowered levels of extraversion and adult anxiety and depression symptomatology, I suggest that qualitative interviews take place with SDI in order to tease out any residual feelings of upbringing that may have unduly affected them.

It has been suggested that parental reaction to raised stress levels of looking after children with problems could include increased irritability, alongside an increased critical and punitive approach towards the child (Webster-Stratton, 1990). Studies have suggested that looking after a child with ASD is a highly stressful situation, due to lack of reciprocal, emotionally fulfilling interactions with the child and the maladaptive behaviours that often characterise an ASD individual (Blacher & McIntyre, 2006; Eisenhower, Baker & Blacher, 2005). It is thought that due to the lack of emotional or social reciprocity from ASD individuals that the reactions to these stressful situations could then be exacerbated in the parents of ASD children by parental emotional and /or physical withdrawal as a type of parental coping mechanism due to the suggested 'extreme burden of care' placed upon these parents (Osborne & Reed, 2010, p. 412).

It should be considered that the parent might conceivably have the same behavioural reactions to their child without the disability; this could be due to over-exhaustion or a feeling within the parent that the child without disabilities should somehow be able to control any negative behaviour, due to the increased capabilities that they have relative to the child with disabilities. This suggestion was not directly tested within the study but there is a need for research to address parental reaction to the SDI when the parents are in positions of perceived stress (Hastings, 2002). It could help to explain the relationship between having a disabled sibling and perceived inconsistent mothering. If a mother's pattern is to withdraw (Osborne & Reed, 2010), or to act in a more irritable, critical or punitive manner (Webster-Stratton, 1990), due to her raised stress levels, at a time when her child without disabilities needs their help or attention, but resumes being cheerful and loving when the stress levels drop, the child might come to view her actions as inconsistent, which in turn could lead to the development

of affective disorders (DeKlyen & Greenberg, 2008; Mikulincer & Shaver, 2007) as the findings of this study have demonstrated, most specifically for the siblings of ASD individuals.

Giallo & Gavidia-Payne (2006) indicate that high levels of parental stress are a marker for adjustment difficulties for the SDI. Similarly, another study suggests that the directional effect between the behaviours of developmentally disabled children influences parental stress, which can then have a further impact upon parenting behaviours (Hastings, 2002). The author developed a model that can be usefully employed as a template to indicate the variables potentially influencing the directional associations between child behavioural problems, parental coping and self-efficacy beliefs, potentially leading to parental stress; this can then have an effect on parenting behaviour. If negative, this can have a cyclical detrimental effect upon the child's behavioural problems. Whilst Hastings' research does not directly examine the siblings of developmentally disabled children, the process is similar to the transactional model of development proposed by Sameroff and Chandler (1975). This model suggests a bi-directional influence of nature and nurture, whereby not only does the parent influence the child's behaviour but that the child also has a direct impact upon the parent's behaviour. It was postulated that a child with a happy disposition will make the parent happier and consequently will elicit more positive responses from their parents, which in turn will encourage the child to carry on being happy. The converse, however, is also true. Furthermore, because it is an interaction it takes both parent and child to respond in a mutual way to elicit the happy or angry response. I, therefore suggest that if the parents are stressed by the behaviours of their disabled child this will in turn have a direct impact on the direction of their parenting behaviours towards their children without disabilities; possibly, in turn, having an influence upon the SDI's personality traits. The model also showed how adverse events can have an impact upon resiliency, with those with the happier dispositions tending to be more resilient than those without. This theory could explain the cumulative effects of the disability upon the sibling's affective responses but will require further investigation.

Given the increased levels of affective disorders in the adult ASD and PWS siblings found in my studies, the possibility was considered that from an early age children whose siblings have disabilities assert substantial control over any of their own negative behavioural tendencies. This could be as a response to witnessing increased parental stress and a subliminal recognition that by regulating their own behaviour they could help to alleviate parental stress; however, this suppression might have added to their own long-term

internalising issues. This might be particularly relevant as research has indicated that there is a bidirectional effect between problematic behaviour from the disabled sibling and an increase in parental stress and vice versa (Hastings, Daley, Burns & Beck, 2006; Orsmond et al. 2003). This appears to be a particular factor in children with ASD (Lecavalier, Leone & Wiltz, 2006) but, the same effect could probably also apply to PWS siblings.

However, the current results do support the findings of Moskvina et al (2007) who reported that earlier age onset of depression can be associated with childhood trauma but found no significant association between childhood trauma and adult neuroticism and extraversion. They suggest, however, that childhood trauma should include factors such as emotional neglect due to it being a chronic long-term stressor that can influence stress reactions and therefore should be considered an important factor in the aetiology of depression. My study does not imply any intentional maternal neglect; however, force of circumstance through the additional demands of caring for a disabled child (Emerson et al. 2006; Moore et al. 2002) may have led the SDI to have subliminally perceived maternal emotional neglect, thus elevating neurotic tendencies. Again future longitudinal research is suggested to establish if there are any causal effects between parenting styles and the manifestation of high neuroticism levels and low extraversion levels in SDI. Also further information on the relationship between perceived parenting styles and personality traits may be achieved by using a more detailed questionnaire regarding the parenting styles, such as the 'Parental Bonding Instrument' (Parker, Tupling & Brown, 1979) or the 'Childrearing Styles Questionnaire' (Arnold, O'Leary, Wolff & Acker, 1993).

I suggest that the SDI might have internalised feelings that their mother was acting inconsistently or ambiguously towards them as children (Moore et al. 2002), which, in line with attachment theory, would have diminished their feelings of self-worth and increased the potential towards attachment-related anxiety (Nakash-Eisokovits et al. 2002). However, I further propose that as the SDI became older, they had a greater capacity to rationalize the reasons behind the parental perceived unreliability and unavailability and recognised that the maternal behaviour was out of her control (Crnic et al. 1983; Powell & Gallagher, 1983; Rossiter & Sharpe, 2001) and not intended against them personally; this might have alleviated them from personal guilt (Atkins, 1991) and had a buffering effect against the development of affective disorders as a result of parenting style. A cognitive response process might have developed within the SDI, where, despite their intrinsic attachment-related anxiety style, they might have also developed a protective factor, such as coping strategies,

against depression by intellectually understanding the perceived parental inconsistency towards them was not through parental choice. Children would be aware that if their disabled sibling was displaying inappropriate or dangerous behaviour that the parents would need to deal with it immediately; the same might necessarily go with medical routines that might indeed mean survival for the child with disabilities (McHale & Gamble 1989; Moore et al. 2002; Rossiter & Sharpe, 2001) and so somehow the SDI have managed to disassociate parental behaviour from adult affective disorders. This proposal, again, would benefit from further attention. The adult SDI might have realised that they did experience emotional love as a child, just not as much physical availability of the parent as they might have wished for.

Conversely, the control group might not have been able to realistically justify any parental inconsistency and consequently develop the notion that their parents were being inconsistent through choice; which might have resulted in one of the underlying reasons for the development of their depression symptomatology relating to maternal inconsistency. It must be remembered that the development of attachment involves cognitive, affective and behavioural representations, which could perhaps further explain the above results (Bowlby, 1991; Collins et al. 2002).

To conclude, it is important to note that, despite the expected higher prevalence of perceived inconsistent parenting in the SDI group, the fact it had no long-term adverse association with attachment-related anxiety or the reporting of anxiety and depression symptomatology is surprising. It appears from the evidence seen that the lack of association might be due to the SDI who reported inconsistent mothering recognised it as a realistic necessity and have rationalised the reason why it happened; consequently, the cognitive processes have allowed few ill-effects, in terms of anxiety, depression or attachment-related anxiety, which they can relate to inconsistent mothering, have been carried through to adult life. This, I suggest, is a topic that warrants much further exploration, possibly through qualitative analysis in order to tease out finer details of reflections of the SDI's early lives.

4.5The effects upon the SDI of attachment-related anxiety

Initially, as previously reported, it is important to note that the majority of participants from both groups reported secure attachment styles, which offers support to Gass et al (2007) who suggested that higher stressors in childhood do not necessarily increase the lifelong

propensity towards affective disorders. However, the SDI group reported significantly higher levels of attachment-related anxiety when compared to the control group, which supports the research hypothesis. Further, attachment-related anxiety demonstrated a significant mediating path between having a disabled sibling and anxiety and depression because when attachment-related anxiety was added to the model, the path was reduced in size. However, the path was not reduced to zero (see Figures 4.1 and 4.2), therefore attachment-related anxiety was a highly significant partial mediator between having a disabled sibling and anxiety and / or depression (Baron & Kenny, 1986; Kenny, 2009). This meant attachment-related anxiety could help to explain why having a disabled sibling could predict anxiety and /or depression symptomatology (Frazier et al. 2004). Therefore, the fifth hypothesis was also supported. It should be noted that attachment-related avoidance for the SDI group did not significantly differ from the control group and was consequently excluded from analyses.

Attachment styles are formed early in life, dependent upon the quality of caregiving that the individual received (Bowlby, 1973, 1980, 1982; Shaver & Mikulincer, 2008). These styles are then often habitual or can be reverted to as a prototype in times of stress. Due to the increased rates of attachment-related anxiety within the SDI, it suggested that events were occurring within the family life of the siblings of disabled individuals which caused the prototypical attachment-related anxiety response as adults.

It should be noted that my study was cross-sectional and consequently did not measure attachment in the SDI as children; future research could possibly address this; particularly as Waters et al's (2000a, b) and Hamilton's (2000) findings have suggested the stability of attachment over time. Bowlby (1982) suggested that secure and insecure attachment might develop as branching pathways and consequently the more ingrained or reinforced the pathway becomes as a result of caregiving or environmental factors, the more resistant these pathways, or internal working models, would be to change. Hamilton (2000) suggested that this continuity of style is most obvious in children on an insecure attachment trajectory as a result of a process of negative life events. Whilst there was no suggestion that having a sibling with disabilities is a negative life event, it likely brings with it a set of life stressors not normally experienced by the general population (Rossiter & Sharpe, 2001). Further, it should be noted that as opposed to the SDI suffering specific individual negative life events, the stressors involved in the care of a disabled individual tend to be continuous, with the added potential of highly stressful behavioural and medical incidents (McHale & Gamble, 1989; Moore et al. 2002). Consequently, the highly significant prevalence of the

adult SDI's to attachment-related anxiety might be as a direct result of the continuous and potentially on-going set of life stressors due to the care that is required by the disabled brother or sister.

If there had been a caregiving pattern of the SDI towards the disabled sibling in childhood, this might have been maintained into adulthood and thus the SDI might still be in a state of constant hyper-vigilance in order that the well-being of the brother or sister can be assured, which is a symptomatic state of attachment-related anxiety (Mikulincer & Shaver, 2007; Simpson & Belsky, 2008). Or they might conversely have subliminal feelings of resentment that they have put the needs of the disabled sibling before their own requirements which, again, is characteristic of attachment-related anxiety (Carnelly et al. 1994; Nakash-Eisokovits et al. 2002).

The prevalence of the SDI towards attachment-related anxiety indicated a low model of self, where they could experience a complex mixture of negative affect; where a lack of self-resilience can be teamed with feelings of hostility, self-blame, fear and sadness (Mikulincer & Shaver, 2007). A suggestion for this might be that attachment-related anxiety has been maintained as a result of subliminal feelings of guilt due to them being able to do and experience so many more things than their disabled sibling and they might experience self-blame as a result of feelings of 'not doing enough' for their sibling (Atkins, 1991). They might have considered these negative feelings towards their sibling as one over which they have overt control but are subliminally choosing to do little about, which could bring feelings of anxiety within themselves as they try to preserve the sibling relationship (Mikulincer & Shaver, 2007).

Or, indeed, it might be that the SDI had feelings of guilt because coming from the same genetic stock, it could so easily have been themselves that suffered from the disability. This has been described as 'survivor guilt' (Siegel, Silverstein & Elliot, 2001, p.96) which, speculatively, is sure to bring about a complex set of emotions potentially resulting in the negative affect patterns that Mikulincer and Shaver (2007) described. A possible way of overcoming this problem might be that early in the SDI development 'reality checks' are put in place, where knowledge regarding the disability is shared and realistic expectations are explained by the parents and discussed with the SDI as to their present and future role in the care of their disabled sibling (Eisenberg et al. 1998; Giallo & Gavidia-Payne, 2006). This would be to prevent them imagining that they have lifelong demands placed upon them

regarding the care of their disabled sibling, which they might feel incapable of dealing with. Bretherton (1992) suggests that attachment is based in reality, not in imagined experiences, so open honesty and support from an early stage might relieve the SDI of anxious feelings about the future. Heller and Kramer (2009), while not coming from an attachment perspective, support the notion of early and full involvement of the SDI when discussions regarding the disabled sibling's future are taking place as knowledge can alleviate tension within the SDI.

Attachment-related anxiety can have a sub-optimal effect on life and is usually indicative that the individual has low self-efficacy, and has difficulties in maintaining intimate relationships due to their high need for approval and their fear of separation, which they could often respond to with anger (Bartholomew & Horowitz, 1991; Shaver & Mikulincer, 2008). These tendencies towards being unable to regulate interactions with others, which could decrease benefit derived from social support, could potentially lead to a higher incidence of affective disorders (Fraley & Phillips, 2009; Mikulincer & Shaver, 2007; Simpson et al. 2006; Shaver & Mikulincer, 2008).

Attachment-related anxious individuals have constantly hyper-activated attachment-systems (Shaver & Mikulincer, 2002), whereby they are very dependent upon their partner and tend to validate themselves through their partner's responses. However, if there are perceived negative responses, their lack of self-worth might be further diminished; consequently, they generally do not express anger, but internalise it (Mikulincer & Shaver, 2005), which can then develop into affective disorders. Future research might wish to investigate the attachment styles of the partners that the SDI chooses. This is a potentially very important area of study because this study has indicated a significant effect of relationship satisfaction in playing an important protective role against anxiety and depression symptomatology. Therefore, a more in-depth study whereby the partner completes an attachment measure might be worthwhile, in order to ascertain if the SDI are perhaps satisfied in fulfilling their partner's needs, as they did for their disabled sibling, but not having their own needs met (Whiffen, Kallos-Lilly & MacDonald, 2001). This could be a potential problem because of the high rates of SDI attachment-related anxiety meaning a higher propensity towards dependency upon the partner and lack of belief in their own self-efficacy; if the relationship should break down, the negative reaction to this failing could significantly intensify habitual affective negative responses (Shaver & Mikulincer, 2008). Particular vulnerability factors, such as attachment-related anxiety, can be triggered by

pressurised situations, which could lead to a cyclical downward spiral effect by intensifying the attachment response and subsequent affective disorder (Shaver & Mikulincer, 2008).

While it is not possible to alter the fact of having a disabled sibling, it is possible to potentially alter insecure attachment trajectories (Mikulincer & Shaver, 2007; Shaver & Mikulincer, 2008). With this in mind and the ever-growing acceptance of the benefits of utilizing attachment theory in regulating patients with underlying mental health issues (Hinnen et al. 2009; Mikulincer & Shaver, 2007), it would be worth a physician considering using an attachment perspective when treating an individual with a disabled sibling who presented with an affective disorder. Further, it could also perhaps be used as a screening process for prophylactic care in those individuals who present with either previous episodes of affective disorders or those whose backgrounds indicated attachment issues (Bifulco et al. 2006).

4.6 The effects upon the SDI of personality traits

The results of this chapter show that both groups followed roughly the same pattern of the adaptive trait of agreeableness having the highest score and the less adaptive trait of neuroticism having the lowest score. However, there were higher levels of neuroticism and openness and lower extraversion scores for the SDI group. The traits of conscientiousness and agreeableness were not significantly different between the SDI and control group. The traits of neuroticism, extraversion and openness did not support the Lounds-Taylor et al (2008) study, which found no difference for any of the five traits between an adult SDI and a comparison group. It was also found that neuroticism was highly significant in mediating the relationship between having a disabled sibling and anxiety and depression. Extraversion had a more modest, but still significant, mediating influence in ameliorating anxiety and depression symptomatology. However, openness, while showing a definite directional trend towards alleviating depression, was found to be a non-significant mediator.

The SDI results in the present study could perhaps be explained through Rossiter and Sharpe's (2001) suggestion, whereby an issue that affected one member of a family would have an effect on all of the family members. A family with a disabled member would be expected to be emotionally impacted in some way; it might be that increased neuroticism and decreased extraversion levels are the outcome in some of these families. Other research found

that a sample of siblings of disabled children experienced more emotional difficulties and peer problems (Giallo & Gavidia-Payne, 2006); while that study did not look directly at the effects on personality traits, these difficulties appeared to be symptomatic of the neuroticism trait. Rosenman and Rodgers (2006) argued that adverse events that happened in childhood would have the enduring effect of increasing negative affect on subsequent episodes throughout the lifetime. Due to the clinical significance of this they further outlined the necessity of clinical services being aware of the background of the individual, in order to ensure their long-term welfare.

The taxonomic framework of neuroticism measures facets that are implicit in the development of anxiety and depression. Children who score highly on neuroticism tend to be characterised by features such as being highly-strung, unable to deal with stress, low levels of self-esteem, high in feelings of guilt and not sure of their ability to cope adaptively in interpersonal relationships (Shiner & Caspi, 2003). In adults, high neuroticism levels manifest in general negative emotionality, inability to cope with stressful situations and to experience emotionally negative relationships (Jylhä & Isometsä, 2006). The last factor did not appear to affect the SDI group under study due to them reporting the main order effects of slightly higher relationship satisfaction scorings than the control group and tend to be in a relationship of long duration, both of which are factors that should promote emotional wellbeing . Consequently, it appears that whilst the SDI group undoubtedly reported higher levels of anxiety and depression symptomatology, higher levels of neuroticism and lower levels of extraversion, they are able to rely on social support systems when available, which, hopefully ameliorates some of the negative affect. To support this, the results from my study show the ameliorating effect of relationship satisfaction when used as a controlling variable in the extraversion model in alleviating depression symptomatology that is potentially caused by having a disabled sibling.

As expected, the SDI scored lower on levels of extraversion than the control group; this might be due to limited availability of social opportunities when younger, due to the disabled sibling's behaviour possibly being problematic (Stoneman et al. 1988). The taxonomic description of extraversion involves the extent to which the individual actively seeks out social encounters or tries to avoid those (Shiner & Caspi, 2003). It is possible that the SDI cohort was more likely to be socially withdrawn, due to embarrassment or a protective feeling towards their disabled sibling, and showed a degree of reluctance when initially meeting new people. This could be differentiated from being shy or less assertive

around people that were known to the individual and this type of emotional withdrawal could occur if they had previously been snubbed by others (Muris et al. 2009; Shiner & Caspi, 2003). This type of social withdrawal is common in children whose siblings have ASD and they reported feeling lonely and isolated (Bägenholm & Gillberg, 1991) and if the pattern continued, it could explain the results from my study of lowered extraversion levels. It could also further help to explain the higher tendencies of the SDI cohort to report anxiety and depression symptomatology because there have been clear associative patterns established between low levels of extraversion and affective symptom reporting (Watson et al. 2005).

The more significant positive association between the SDI group and openness when compared to the control group was expected. A description of openness includes depth of thought and complexity of life events alongside a willingness to try new experiences (Shiner & Caspi, 2003). Previous studies have found that adult SDI were less embarrassed about the situation regarding their disabled sibling, less concerned about social stigma and less worried about being isolated from their peers than a comparison adolescent group (Seltzer et al. 2009; Wilson, McGillivray & Zetlin, 1992). This implied a greater direction towards openness as the SDI aged; whereby they were willing to embrace new experiences and not be tied to conforming to social norms (Seltzer et al. 2009).

The traits of agreeableness and conscientiousness were found to be non-significant. This was surprising as it was expected that SDI conscientiousness would be significantly higher than the control group; a lot of individuals with disabilities require a rigidly adhered to routine or they become distressed (www.downs-syndrome.org.uk/information/html; National Autistic Society, 2010; Prader-Willi Syndrome Association of Victoria, 2011); it was thought that as SDI became established in the routines and caregiving of their disabled sibling that conscientiousness levels would rise. The same scenario was true with agreeableness; it was expected that due to the additional caregiving (Moore et al. 2002) and support (Lounds-Taylor, 2008) that the SDI was likely to give that agreeableness levels would rise. However, this was not found to be the case, which are complimentary findings to the present study.

Personality traits were investigated in order to try to explain the relationship between having a disabled sibling and adult anxiety and /or depression symptomatology; it was found that higher levels of neuroticism and lower levels of extraversion within the SDI mediated, or explained, the relationship. It was, however, found that openness had no significant mediating effect on either anxiety or depression.

Watson et al (2005) suggested that neuroticism, while a consistent marker of psychopathology, was most strongly associated with chronic and persistent symptoms of subjective distress and dysphoria; whereas lowered levels of extraversion were a more consistent marker of depressed affect and social anxiety. My study was broadly supportive in the significance and direction of the personality traits, particularly for neuroticism, which highly significantly mediated the relationship between depression and, more particularly, anxiety and having a disabled sibling; extraversion, however, had a more modest mediating effect on both anxiety and depression.

It was suggested by Watson et al (2005) that the aetiology of the associations between personality traits and specific affective disorders could be as a result of three reasons, which they termed the vulnerability model, the complication model and a shared underlying model. In the vulnerability model, the premorbid temperament of the individual wields a causal influence upon the likelihood of them developing a specific disorder. The trait might then influence the direction or severity of the disorder, which was regarded as the pathoplasty model. Secondly, the complication model suggested that it might be that the disorder had a temporary influence on the particular personality trait; if it was a permanent influence it was then referred to as the scar model. Lastly, they suggested that temperament and particular affective disorders might share an underlying aetiological basis, possibly genetic, which was influential in the development of both personality and affective disorders. This was a dimensional approach, whereby normal and abnormal affective processes were proposed to continue along the same line and that it was differences in individual temperament that showed subclinical indicators of affective disorders. Watson and his colleagues' work appeared to develop models that had been previously reported; however, previous research also included the 'spectrum association' model, which suggests that psychopathology represents the extreme ends of personality traits (Salekin & Averett, 2008). Another suggestion is the 'resilience model'; whereby personality traits might have a protective influence on the development of psychopathologies (Shiner & Caspi, 2003).

Research has shown that students with high levels of neuroticism are significantly more likely to develop depression symptoms as a result of vulnerabilities to stressors over daily hassles (Hutchinson & Williams, 2007). The authors suggest this is due to the vulnerability model, whereby the traits can be predictably associated with specific disorders (Watson et al. 2005). Hutchinson and Williams suggested that the moderating effect found may be due to 'raised emotional and physiological reactivity to negative events' (p. 1375).

They further suggest that the mediating influence between neuroticism and depression symptomatology exerted by daily hassles can be due to individuals with high levels of neuroticism reporting more incidents than those low in neuroticism; the authors could not, however, establish if they did actually experience more stressors or just perceived that they did. However, the SDI might have experienced actual stressors (Moore et al. 2002). These stressors could include poorer family functioning, lower levels of pro-social behaviour (Giallo & Gavidia-Payne, 2006), the need to excel (Moore et al. 2002; Powell & Gallagher, 1993), raised embarrassment levels and increased caregiving tasks, in respect of their disabled sibling (Turnbull & Turnbull, 1993), all of which might have exacerbated the tendencies towards increased neuroticism levels and development of the vulnerability model towards affective symptomatology. This, in turn, might have led to the pathoplasty model (Watson et al. 2005), which could influence the severity of the affective disorder; depending upon how many of the aetiological stressors were interacting.

Studies focusing on the recurrence of depression in later life have found significant associations with neuroticism (Steunenberg, Beekman, Deeg & Kekhof, 2009a; Steunenberg, Braam, Beekman, Deeg & Kekhof, 2009b). These studies indicate that in younger samples, higher levels of neuroticism predict recurrent episodes of depression. Whilst the first study (a) did not directly measure anxiety, the authors suggested that persistent anxiety might be the 'active ingredient' (p.71) in the interaction between residual depression symptoms and later life recurrence of depression. The second study (b) predicted that the impact of personality traits on depression symptoms lessened as the person ages, due to other factors, such as health impairments, taking priority over particular traits. My findings partially supported the previous studies in that neuroticism was highly significant in mediating depression as likewise, in their studies, neuroticism also predicted the relationship with depression. However, the Steunenberg et al study (2009b) found no significant associations with extraversion; whereas my study showed that extraversion had a significant mediating effect upon depression, albeit, not to the extent of neuroticism. My study, however, offered no support to their findings that the effect of personality traits upon depression lessened with age (Steunenberg et al. 2009b) as there was no association with neuroticism, extraversion, openness and age found.

In a similar vein to my study, Spinhoven et al's (2011) research tried to assess if neuroticism and extraversion predicted anxiety and depression and if life events could then moderate the symptomatology of these conditions. They also tried to establish if life events

mediated the relationship between neuroticism, extraversion and affective symptomatology. They found that the impact of neuroticism on depression was significant in the prediction of depression; whereas high levels of extraversion had an ameliorating effect on both anxiety and depression symptomatology. However, my study also found a highly significant predictive effect of neuroticism upon anxiety symptomatology and that neuroticism was highly significant in explaining the mediating path between having a disabled sibling and anxiety. This overall difference in findings helped to emphasise the different aetiology between anxiety and depression developmental courses and whilst there might often be a significant degree of co-morbidity between the disorders, they should usually be examined as separate entities.

The difference in my results for anxiety when compared to the results of Spinhoven et al (2011) might be explained by the fact that the SDI participants in my study are faced with the lifelong 'event' of having a disabled sibling. Within this scenario, there are sure to be an intertwining combination of both positive and negative life events, which probably have an impact on the personality traits of the SDI. Spinhoven and colleagues (2011) looked at the independent effects of positive and negative life events over the previous twelve months; it is suggested that the influence of the longevity of the event has a significant effect upon anxiety and depression symptomatology and personality traits, which possibly become entrenched over the lifetime period compared to the more transient effects of twelve months. This effect should be considered in future research with adult SDI.

Interestingly, my study showed that despite the SDI group reporting higher levels of openness in comparison to the control group, it is not a significant mediator between having a disabled sibling and depression symptomatology. While openness has generally not shown the same degree of consistency in predicting the course of affective disorders (McCrae & Costa, 1991; Ready & Robinson, 2008), it shows a definite trend towards alleviating depression symptoms in the SDI in this study. Openness measures facets of personality such as curiosity, imagination, intellect and the willingness to try new experiences (Shiner & Caspi, 2003). The reasons behind the increased reporting of openness by the SDI can be understood due to them possibly having to employ different strategies in dealing with potential behaviours in their disabled siblings; these strategies might need to be imaginative. Also, the SDI may have learned to become accepting of other's behaviour that is not similar to their own (Seltzer et al. 2009); particularly if these behaviours are met with subliminal or overt disapproval from other observers. It is hoped that increased levels of openness may be

something to be encouraged in modifying depression symptoms in the SDI, and, therefore, useful to be aware of in a clinical setting. Whilst there is only a trend towards openness easing depression symptoms in my study, this factor may be worth further investigating in order to fully understand which particular elements of it are likely to be clinically helpful.

4.7 The effects upon the SDI of different disability types

The above results support the first hypothesis whereby the ASD sibling group had an increased tendency to report higher levels of anxiety and depression than the control group and also the DS sibling group. The ASD sibling group also reported higher levels of depression than the PWS sibling group but not significantly so; both groups reported similar mean levels of anxiety. The DS sibling group reported no significant differences in HADS anxiety or depression symptomatology in comparison to the control group.

These results offer some interesting insights into the long-term development of individuals with different types of disabilities. When the disability types were compared to the control group for anxiety symptomatology, it was only DS siblings that were not significantly different from the control group on reporting of anxiety or depression symptomatology. This supported previous research, whereby having a sibling with DS does not inevitably cause poor levels of adjustment (Cuskelly & Gunn, 2006). These authors further suggested that if a sibling should present with problematic behaviour or outcomes, then it should be addressed on a within-family basis as opposed to the more imprecise group membership.

Research focusing on comparing the adult relationships between DS and ASD individuals and their siblings has found that the siblings of DS individuals do considerably better than ASD siblings on the overall quality of the sibling relationship; they score higher on measures of general health and report lower rates of depression symptomatology (Hodapp & Urbano, 2007). These authors relate this to the ‘Down syndrome advantage’ and the postulated reasons for these findings include the more socially reciprocal aspects of the DS character, lower levels of behavioural problems, being associated with a widely recognised condition and increased maternal age; which is equated with more maternal experience and being more likely to access support groups. The authors suggest that these results could have important implications for the future roles of the sibling relationship, whereby the positive

characteristics and increased quality of the relationship should help to promote increased positive contact as the siblings become older.

This is of increasing importance as parents age and despite them often maintaining 'careers' (Krauss et al. 1999, p.83) as parents of their disabled siblings, there comes an inevitable stage where they cannot sustain this role; this is often when the sibling steps in to assume responsibility (Krauss et al. 1999). With increasing government cutbacks in welfare provisions (Hodapp & Urbano, 2007), the role of the siblings might affect not just the future welfare of the disabled siblings but also future policy development (Krauss et al. 1999). Policy decisions may not explore the actual differences between the disability groups but it should be considered that those with ASD siblings might find it potentially more difficult to care for their siblings than, for example, DS siblings (Orsmond & Seltzer, 2007a). Esbensen et al (2010) pointed out that ASD individuals not only received fewer services than their DS counterparts but also that the ASD individuals had more needs that were unmet by services. This lack of help might be a contributory factor in the affective aetiology of the ASD siblings. Further research needs to be undertaken to establish the long-term caregiving potential of siblings of those with different disability types, to ascertain if they have different characteristics or needs.

However, previous research has indicated no behavioural adjustment differences between siblings of children with DS, ASD and mixed aetiology mental retardation (Hastings, 2007). When compared with a control sample, it was found that those with siblings with DS were better adjusted; this was generally supported by my study, which found lower affective levels for DS siblings in comparison to ASD and PWS siblings. The same research also found that siblings of individuals with ASD and mixed aetiology mental retardation reported less hyperactive behaviour than the control sample (Hastings, 2007). The author put forward some very cohesive suggestions for these results, which included that due to the report being based on maternal reporting, the mother could have been influenced by the potential positive bias of having a child with DS and reported the ensuing positive impact upon the sibling. Hastings (2007) also suggested the fewer hyperactive behaviours in siblings of those with ASD or mixed aetiology mental retardation reported in his study in comparison to the control sample might have been due to the mothers comparing the siblings to their disabled child and finding the behaviour of the siblings without disabilities behaviour relatively less disruptive. Similarly, another study stressed the contrast between the positive adjustment of the ASD siblings and the social and emotional difficulties of ASD individuals;

the authors expressed surprise at these findings due to the stressful conditions that the ASD siblings are perceived to live under (Pilowsky et al. 2004). This adjustment pattern appeared not to carry through to adulthood as the results from my study clearly indicate the higher levels of affective symptomatology that siblings of ASD individuals, in comparison to other SDI, are prone to post-childhood.

The findings from my study indicate no significant long-lasting affective problems of having a DS sibling and so it could be speculated that there might be little comparative difference between being brought up in a normally functioning household, with its own sets of ups and downs, and being brought up in a household with a DS sibling. This could possibly be due to the fact that DS is a disability that is easily recognisable, non-threatening and well accepted by the general public. This combined with the stereotypical happy, sociable nature of the DS individual could explain why there was no significant difference in anxiety symptomatology between the DS and the control group. The slightly higher scoring on anxiety and /or depression symptomatology than the control group might be due to the additional stressors of worrying about the long-term care for their DS sibling, or perhaps their DS sibling's increased propensity towards dementia as they age (Rosner et al., 2004; Sleegers et al., 2006). These topics were not within the scope of this study but would be worthy of future research.

The reasons behind the ASD and PWS sibling groups, raised tendency towards adult anxiety and depression requires further investigation. New research might focus on the lifelong behavioural difficulties of the ASD and PWS individuals; whereby the lower functioning individuals require constant monitoring in order to ensure their well-being (http://www.disability-resource.com/Autism/autism-in-adults.html). This would be expected to have either a subliminal or overt affective influence upon the SDI, depending upon how involved they were in their sibling's day-to-day care needs. If the involvement is on a regular basis, it might take an emotional toll, leading to anxiety and depression symptomatology as it can do in mothers of autistic individuals (Baker, Seltzer & Greenberg, 2011). If, however, the sibling plays a distant role, it might be feelings of guilt that lead to affective symptomatology (Atkins, 1991).

My research examined differences between DS, ASD and PWS siblings. This is a novel concept as the PWS group has not been previously examined in this context to the best of my knowledge. The results found that the adult PWS reporting of anxiety and depression

symptomatology were extremely similar to the results of ASD siblings; however, when looked at in depth, the variables to explain the causes of the symptomatology varied. The ASD sibling group show that inconsistent mothering was significantly associated with anxiety and that attachment-related anxiety was significantly associated with depression, in contrast to the PWS group which shows very little association with these variables; however, the PWS sibling group shows a significantly higher association between neuroticism and anxiety than the ASD group. This would be interesting to investigate further to try to establish if it is the nurturing aspects of the early familial setting for the ASD that increases the tendency towards later reporting of anxiety and depression symptomatology.

Previous research has indicated strong similarities in some of the manifestations of PWS and ASD individual behaviours, such as poor social interactions, temper tantrums, susceptibility to stress and repetitive, ritualised behaviours (Dimitropolous & Schultz, 2007; Veltman et al. 2004). This might help to explain the similarity in affective results, which, speculatively, might indicate that particular responses to specific behaviours might result in the affective pattern that is witnessed here. It could be that, in contrast to the positive general response that DS individuals receive, the opposite is true for individuals with ASD or PWS. If there are public displays of maladaptive behaviour from the disabled siblings, it could have the result of intense embarrassment or frustration for the SDI, possibly dependent upon the public reaction. Previous research has suggested increased levels of stress within Prader-Willi families and that the PWS individual's maladaptive behavioural and social tendencies would require lifelong management (Rosner et al., 2004). Consequently, as opposed to the sibling relationship being mutually supportive, it could actually have the long-term effect of lowering self-esteem or creating other adjustment problems in the SDI (Hastings, 2007).

Future research would do well to expand this theory to the effects on siblings of different, untested disabilities, in order to try to establish if particular underlying characteristics of disabled siblings, or particular responsive parental behaviours, are instrumental in the development of SDI affective disorders. Perhaps, if any factors can be identified, they might be able to be modified within either the individuals creating them, or the SDI might be advised of specific strategies that could help to alleviate or avoid the distress that they have absorbed.

Despite the increased prevalence of attachment-related anxiety for the SDI group as a whole, it would appear that with the specific sibling groups examined here that this did not

happen. The only significant associative finding was between the ASD sibling group and perceived inconsistent mothering. Further investigations as to the developmental path of attachment-related anxiety should still be investigated though, in order to establish whether particular situations played a role or if it was on-going events. This would ideally be best researched through semi-structured interviews, which would allow the siblings of each disability type the opportunity to make connections with past events as opposed to using the more perfunctory self-report questionnaire.

Life experiences are influential in the malleability of personality traits (Edmonds et al. 2008; Srivastava et al. 2003). My research found higher rates of neuroticism and lower rates of extraversion reported by the ASD sibling group compared to the other groups; albeit these differences were not significant. The PWS sibling group also reported similar levels of neuroticism to the ASD siblings. These are interesting findings because, as previously reported, to bring up a child with ASD is supposedly one of the most stressful parenting tasks that there is, even in comparison to other disability types (Orsmond & Seltzer, 2007b; Osborne & Reed, 2010). This is bound to have an effect on the SDI, whether in parenting terms or as an influence in the SDI's reaction to the ASD sibling; the exact effect is still not clear due to the complexity of the relationship between personality and affective disorders. It could be that the ASD sibling group have a 'latent vulnerability' to depression (Lang & Farmer, p.59) that is exacerbated by the disabled sibling's behaviour or by something relevant in the upbringing of the sibling. It could be a complex interaction between environment and personality traits creating a co-morbid disorder, leading to heightened affective symptomatology (e.g., Spielberger, 1966). Or, it could also be that state and trait might have had an influence on ASD siblings; speculatively, the ASD siblings could have had internal reactions to different situations played out by their disabled sibling, which might have influenced their current personality, creating a greater emphasis on traits such as neuroticism and extraversion (e.g., Clark et al. 2003). Trait and state personality measures both correlate with the severity levels of depression, whereas changes in state correlate with changes in severity level of depression (Clark et al, 2003); speculatively, if incidents relating to the ASD sibling occurred over a prolonged period these state reactions might have become incorporated as a more persistent sibling pattern of increased susceptibility towards affective disorders. A similar pattern might also cause the affective patterns witnessed in the PWS sibling group.

In contrast, the associations between the DS sibling's personality and their control group is very similar, perhaps indicating overall less stressful events that occurred in comparison to being brought up with an ASD sibling (Hodapp & Urbano, 2007; Orsmond & Seltzer, 2007a). The pattern is also set, whereby the ASD siblings reported the highest anxiety and depression symptomatology of the groups under examination and these heightened levels of neuroticism and lowered levels of extraversion are closely associated with particularly anxiety symptomatology (Lang & Farmer, 2007) and also depression (Trull & McCrae, 2005; Watson et al. 2005). The ASD sibling traits could potentially have resulted from lowered pro-social tendencies as a result of worry over the ASD sibling behavioural displays (Giallo & Gavidia-Payne, 2006) or decreased access to social activities (Seltzer et al. 2009) and then cyclical lack of perceived social support (Stoneman et al. 1988). Indeed, research has shown that children whose siblings have ASD have reported feelings of isolation and a typical reaction to this was social withdrawal (Bägenholm & Gillberg, 1991). Further research would do well to establish the exact circumstances that cause ASD siblings to be more prone to these maladaptive personality traits, possibly through comparing them to DS siblings, because this could be very useful if the siblings required clinical assistance with regard to their disabled brother or sister. It would also be beneficial to explore the reasoning behind the increased neuroticism levels in the PWS sibling group and whether this is due to certain similarities in the behaviours of the disabled siblings with the ASD individuals.

4.8 Birth order in relation to the disabled sibling

There were no significant differences found between the older or younger groups in differential reporting of anxiety or depression symptoms. Also there was no difference in attachment dimensions found between older or younger siblings of the disabled sibling; however, on closer inspection, a significant difference in the attachment categories between younger and older siblings was identified, where older siblings were more likely to be securely attached. It was also shown that there is no difference in personality traits depending upon whether the SDI was born before or after the sibling with disabilities and again no resultant differences in affective symptomatology. When the different sibling disability type was examined, the only significant difference found was that younger PWS siblings are significantly more likely than PWS older siblings to report increased depression symptomatology.

Levy-Wasser and Katz (2004) suggested that birth-order might play a role in the development of attachment styles; however, in contrast to my study, they found no significant differences in attachment style according to whether the sibling was older or younger than the disabled sibling. The suggestion by Crnic et al (1983) that older siblings, particularly sisters, would experience increased conflict due to having extra caregiving responsibilities was not borne out in attachment style. Hastings (2007) found better adjustment patterns in older ASD siblings and suggested that this could have been due to the development of stronger attachment relationships with their parents before the ASD siblings were born. This is in accordance with Petalas et al's (2009) findings, which also suggested that being younger than the child with ASD was a vulnerability factor. It could hypothetically be suggested that if the older child had time to become securely attached to its mother before the birth of the child with ASD it could help to explain why attachment- related anxiety acted as a significant associative variable between having a sibling with ASD and anxiety and depression symptomatology. It would have been expected that younger siblings would report higher levels of attachment- related anxiety; however, in my study there were no significant differences on the attachment dimensions or on anxiety and / or depression symptomatology between older and younger siblings; with the exception of the PWS younger sibling group having a significantly higher propensity towards depression.

The higher propensity for older siblings to be securely attached in this study could be due to them having previous experience in a less stressful environment, where they could have experienced full attention from their parents before the arrival of the disabled sibling, which could have acted as a protective factor in the maintenance of secure attachment. This is in accordance with the findings from Friedlin and Florian (1996) and also concurred with Dallaire and Weinraub's (2007) findings whereby attachment security from as young as 15 months acted as protection against future anxiety, even if the family experienced stressful life events thereafter. It could be imagined that a potential stressful life event that the older SDI lived through was that of the adverse parental reaction to discovering their child had a disability (Lobato, 1993); it might well have produced considerable periods of emotional turmoil but the maintenance of the older siblings' secure attachment tends to support the results from Dallaire and Weinraub (2007).

The finding that older siblings reported higher levels of secure attachment was in contrast to Boyce and Barnett's (1993) suggestion that older siblings would be at greater risk due to them having had an increased burden, potentially due to them having had to step in as

carers for their disabled siblings or to support other members of the family. If the older siblings had already developed a secure attachment style, it may then be viewed that the extra responsibilities placed upon them as a pro-active approach to assisting with family difficulties as opposed to a burden being placed upon them (Collins & Read, 1990; Griffin & Bartholomew, 1994; Hollist & Miller, 2005; Shaver & Mikulincer, 2002).

The only significant difference in my study in respect to the way that older and younger siblings of disabled individuals perceived parenting styles was that younger siblings perceived colder fathering. Speculatively, this might be explained by the older sibling swapping their allegiances to their father when the disabled sibling was born because the mother's time was taken up with the new and demanding caregiving responsibilities. The relationship with the sibling who was older than the disabled child would already have been established and consequently the father might have found this relationship easier to maintain. This could be in marked contrast to forming a new relationship with a baby born after the disabled child, as by then the father might have developed a caregiving style that was appropriate to a disabled child but which might be inappropriate for a child without the same difficulties; possibly it might be that the mother was so involved with the child with disabilities that the father assumed his parental role was to support the mother. If this pattern of behaviour became established, it might explain why the younger siblings perceived their fathers as acting more coldly towards them.

Concerns that increased caregiving by the older sibling may have had a detrimental influence are unfounded in my study (Crnic et al. 1983). Likewise, the suggestion that younger siblings may experience heightened guilt through suppressing negative feelings towards their disabled brothers or sisters (Atkins, 1991; Seigel, 2001; Stoneman et al. 1991) also appears unsupported in my study. This is because guilt is one of the measurable markers of the neuroticism trait in the Big-Five (Goldberg, 1992) and there is no significant difference in neuroticism between the older and younger siblings. This certainly appears so within the adult SDI group but it might be worth further research.

Speculatively, given the higher prevalence of younger PWS siblings reporting depression symptomatology, it could be that something occurs very early in life that has a lasting effect. While this research showed slightly higher overall depression tendencies of ASD siblings, the results were very similar to the overall PWS tendencies. The adult phenotypical adult characteristics of ASD and PWS can be similar (Dimitropoulos & Schultz,

2007; Veltman et al. 2004); however, autism often does not present until the child is approximately two years old whereas with PWS when the child is born they often present with significant problems (Veltman et al. 2004). Therefore, if a sibling is born soon after the ASD child the parents might be unaware and carry on as normal; consequently there would be no effect as a result of the disability on the new-born sibling. In contrast, a sibling born soon after a PWS child might enter a family experiencing stressful times; this, therefore, might have a lasting affective impact on the younger PWS sibling. These suggestions, however, do not explain the ASD and DS younger sibling's tendency towards significantly raised anxiety levels; the overall findings do suggest that younger siblings have an increased vulnerability towards the affective disorders and the reasons underlying this do warrant further investigation.

4.9 Bias, reliability and validity of measures used in the studies

4.9.1 Self-selection of participants

Initial recruitment of the sibling group was through advertising in national disability support groups. There might have been a degree of bias that occurred here as members of these support groups might already have underlying affective issues that could have caused them to join the support group in the first place. There was further scope for self-selection on the basis that only 150 participants responded out of a total of 273 (55%) questionnaires that were issued from the University. It is not, however, absolutely certain if 273 potential participants received questionnaires due to some of them being issued to the charities, who were to distribute them in order to protect their databases.

As recognized, the majority of the participants for the SDI group were recruited through disability associations; it is often the case that the members of such associations will be better educated, in order to access such self-help and relevant information in the first place, which might skew the results. It should be noted that within this study the SDI group did report significantly higher educational attainment for themselves and their parents than the control group. Further, the majority of participants in this study were middle-classed and Caucasian, so the results might not be generalizable to other siblings with disabled brothers and sisters, particularly as other research has found the majority of children with disabilities tend to come from more disadvantaged backgrounds (Olson & Hwang, 2008).

The 100% success rate for the return of the pilot-study questionnaires was due to them being specifically chosen on the basis of the diversity of their life-styles and ages. Due to them not being anonymous, it was relatively easy to chase these questionnaires if the respondent was late in returning them; however, the lack of anonymity may have skewed some of the results in terms of participant bias.

The requests for participation in the control group were locally based and participants were advised that their responses were needed only to compare them to the disability sibling group. Nine participants were specifically targeted on the basis of their gender, age, marital and socio-economic status, in order to match the reference group case by case, but again these participants were given the same information as the others.

An advantage of the study was that they relied on the siblings' self-reporting as opposed to using maternal reporting, which should have given a truer picture of the relationships between the variables because the adult individual often has a greater insight into their own feelings than those close to him or her. These factors should address concerns of methodological issues raised in previous research, which indicated that previous weaknesses led to inconclusive findings when examining the impact of having a sibling with a disability (Cuskelly & Gunn, 2006).

There is always the issue of the reliability of self-report measures; critics argue that the reported results might be biased due to a lack of true insight on the participant's behalf or participant's deliberate or subconscious responses to portray themselves in a better light (Ganster& Schaubroeck, 1991); this might be relevant due to the sensitive nature of this study. However, self-report measures are good for getting a general idea of the direction of the associations between variables, which can then allow a focus for more in-depth further research. This research could take the form of qualitative interviews, which can give a much deeper insight into recognizing what participants really feel.

4.9.2 Reliability of the measures used

The measures used in this study all had good content, construct and predictive validity. The reliability of the measures had all been previously established; further the internal consistencies measured through Cronbach's Alpha scores in this study were within the high range for the established measures. The only measure that it was not possible to

calculate Cronbach's Alpha scores for was the Descriptions of Parental Caregiving Style (Hazan & Shaver, 1986); this was because there was only one answer for each section of the measure and the test could not then return the level to which the items are measuring the same concept. This could perhaps be addressed if future research is examining parental caregiving by using a different measure that allows for more detailed responses; however, the results produced by the DPCS for the control group were exactly in line with predicted outcomes.

It should, however, be noted that the severity measure used was based on the participants subjective view of their sibling's disability and there was no objective measure of this. There were only four response options to the question of the severity of the disability and no guidance notes were given as to what range of disability should be included with each response option. This should be noted and clarified in future research and if possible medical confirmation should also be included. Or possibly the severity of the disability could be measured through a scale such as the one developed by Lawton, Moss, Fulcomer and Kleban (1982), which measures the disabled individuals abilities on seven activities of daily living, and the level to which they need assistance (ADL) and also on eight instrumental activities of daily living (IADL) and the level to which they require help. Despite this measure being created to measure responses in the elderly, it would also give a more accurate response for disabled individuals.

4.9.3 Convergent and discriminant validity of the measures used

One of the crucial issues raised in this research is the discriminant validity of the attachment styles and personality traits measured. This particularly relates to how far is the ECR measuring emotions, cognitions and behaviours that are specifically related to attachment; or could there be confusion, whereby attachment-related anxiety is actually measuring the broader trait dimension of neuroticism? Previous research has sought to alleviate these concerns and to ascertain the quantitative difference between the measures in order to establish their independence from each other. Whilst there are reported to be consistent overlaps, particularly between attachment-related anxiety and neuroticism, the measures do appear to remain independent, with attachment styles being theoretically better at predicting relationship quality (Noftle & Shaver, 2006; Shaver & Brennan, 1992). The evidence from this study also shows differing results between the constructs, with

attachment-related anxiety being better at predicting relationship quality but with neuroticism being consistently stronger in predicting the affective disorders, particularly anxiety symptomatology. Therefore, there is overall substantiation for the discriminant validity of the measures used here.

With regards to convergent validity, the evidence from this study gave consistently similar findings between the attachment measure of Experiences in Close Relationships (Brennan et al. 1998) and the Descriptions of Parental Caregiving Style (Hazan & Shaver, 1986) in relation to other key variables. This is with the notable exception of the DPCS having no associative value with any of the other key variables for the SDI group, whereas the control group were consistent with expected predictions in their associations. This finding may be anomalous for the SDI group or it may reflect an actual difference between the groups from this study and from previous research. Potential reasons for the atypical findings will be discussed later.

4.10 Evaluation of the study

4.10.1 Strengths of the study

A major advantage of this research was that it used a very closely matched control group. The control group was matched case by case on gender, age, marital status and, where possible, socio-economic status. This ensured that I was measuring like-for-like and therefore, it allowed for very tight control between the variables under investigation. It was, however, a very time consuming task.

The sibling group also had a relatively high number of participants for this type of study, which should allow for individual variation in results. It also increased statistical power, which eased detection of any significant relationship which actually existed within the data. Or, more to the point, it decreased the likelihood of reporting a null hypothesis, when in fact a relationship does exist.

This research addressed some concerns raised by other authors; whereby all the measures were answered directly by the participants and did not rely upon maternal or anybody else reporting upon them (Moore et al. 2002). The results through maternal reporting have a tendency to report more negative outcomes than when self-reporting is used.

Further, these studies also controlled for demographic variables that were shown to be significant in predicting anxiety and depression symptomatology for the cohort. This should then prevent the results from being skewed and present a more realistic picture as to what is actually happening in the affective reporting (Lefkowitz et al. 2007).

An advantage and disadvantage of this research was the number of sibling participants in each disability type group. It was a large cohort overall but when the effects of disability type upon the sibling were examined independently the numbers within each group were not sufficient to carry out large scale analyses. However, it was the overall effect upon the affective outcome in individuals with disabled siblings that the study was examining. An important implication of this is to highlight the necessity of ensuring the welfare of a potential cohort of future caregivers. However, the potential specific clinical or counseling welfare needs of the specific disability types should not be ignored; the aetiology of clinical need is paramount in deciding the course of a treatment but ultimately the needs of the individual should be uniquely addressed (Cuskelly & Gunn, 2006).

4.10.2 Weaknesses of the study

The primary limitation of this study was that it was cross-sectional; therefore there could have been unreported, extraneous variables that were influencing the participant's responses at the particular point in time of completing the questionnaire. Follow-up studies could potentially iron out these issues; I would, therefore, suggest that future research examines the topics raised in this study from a longitudinal perspective. The study was also a survey design, which, whilst being a valid method for collecting information from a large cohort, surveys do not allow me to assume causal effect because there may be other factors associated with the particular group membership other than the disability that could explain the outcomes (Hastings, 2007).

The issue of collecting all the data through self-report is also contentious, due to the possibility of some participants not being objective enough in their accounts of themselves. This can lead to participant bias, which may skew the results. Recent research argues for the use of a combination of qualitative and quantitative data, in order to reach greater depths of understanding as the data then has the benefit of being collected from different perspectives, therefore giving a more balanced overall view (Molina-Azorin, 2012). It should however be

noted that there is the potential issue of measurement bias and any causal inferences made if an error is made in the method through which the interplay between the variables are assessed (Spector, 2006). However, for the purposes of the current research, it is suggested that opposed to relying solely on self-report in future that qualitative analyses, such as semi-structured interviews are also implemented in order to gain a better understanding of the whole picture. If possible, it would also be beneficial to interview another sibling, parent or partner of the SDI in order to gain perspective of the account of the SDI; the other interviewee might shed light on different factors that might have influenced the SDI's reaction towards their disabled sibling, thus giving a more balanced overall research perspective.

Another drawback of the research was that it included a retrospective account of perceived parenting styles that might have been influenced by many other factors throughout the different age-periods. The retrospective design of parenting style means that it is not possible to apply causal interpretations of any of the relationships that were found (Spinhoven et al. 2010). This is due to no accurate measure being taken at the time; this reliance on childhood perceptions of their parents without objective collaboration from the timeframe examined might mean that the perceptions of their parents are now biased, which could skew results. However, there has been a recent defence for the inclusion of retrospective designs due to it being more likely that an overall, balanced perspective is taken of the situation rather than a reactionary one that might be dependent upon recent events, which could bias interpretations (Rohner, Khaleque & Cournoyer, 2011). This appears particularly relevant to my research because it has been argued that adults are more likely than children to express their true feelings and much more able to take a global view on their relationships with their parents (Finley & Schwartz, 2010).

The characteristics of the sample may prevent generalizability of the study; the sibling participants were self-selected and mainly drawn from disability groups, they were all Caucasian and predominantly from the middle classes. Previous research has indicated that few economic concerns may alleviate day-to-day concerns regarding the disability (Olsson & Hwang, 2008); the authors also suggested that more disabled children are born into economically disadvantaged backgrounds (Olsson & Hwang, 2008), which might give different results to the current findings. Further to this it is not known why the participants are members of support groups; it could be in order to find out more about the disability and find out about people in similar situations to themselves or it could be because they already

had underlying affective issues and are seeking help (Lobato & Kao, 2005). It would be interesting to carry out research on the affective outcomes of disabilities of those from different ethnic backgrounds to try to ascertain if they have different outcomes to the Caucasians in this study.

It is clear from the present study that there are many variables that are significant for both groups in the reporting of increased anxiety and /or depression symptomatology. However, when moderation analysis was used to ascertain if the levels of any particular demographic variables might have a moderating effect with having a disabled sibling resulting in increased anxiety and /or depression symptomatology (Frazier et al. 2004), no interactive effects were found. While these results were surprising when working upon the assumption that nothing happens in isolation, it is in line with previous research which indicates that interactive effects in non-experimental studies are very difficult to find (McClelland & Judd, 1993) despite expected theoretical assumptions (Morris, Sherman & Mansfield, 1986). It has been suggested that moderator effects when the changed explained variance is as low as 1%, should still be considered important (Evans, 1985, as cited by McClelland & Judd, 1993).

In this study the only variable that this would apply to was age and having a disabled sibling having a moderating effect upon anxiety; the explained variance here was 1%, whereas all the other variables that were examined had no explained variance at all. McClelland and Judd (1993) proposed that the reason for extremely low interactive effects in non-experimental compared to experimental designs was due to the non-optional distribution of the non-experiment, which in turn reduces statistical power. This might have been a contributory factor to the lack of findings in the present study and future research should be aware of this limitation.

Due to the way that missing data was dealt with, whereby the data was excluded from a sub-section or a section of a scale when the participant from either group had not completed all the questions that were asked on that scale, whilst the matched participant from the other group remained in the analysis, it meant that some of the overall analysis was based on slightly different sample sizes. Whilst this maintained overall statistical power, it might have skewed some of the data. Further research may benefit from excluding the matched participants from both groups, whilst this might slightly reduce statistical power, it would at least deliver more precise results for a matched design.

4.11 Directions for Further Research

Due to the speculative nature of this research, many suggestions for further research have already been mentioned; however, future investigation would benefit from qualitatively interpreted semi-structured interviews. Whilst this would necessarily involve a smaller cohort, it would allow for a much wider range of information to be gathered and connections to be made in order to establish the crux of the inter-relationships of family life with a disabled sibling. This would be rather than relying on set responses from a large cohort. New, as yet unexplored, avenues might be opened up from chance and unexpected remarks that could help explain the SDI's increased propensities towards affective disorders.

Future research would also benefit from taking a longitudinal perspective, investigating family experiences in childhood and then following up individuals at different stages across their lifespans. Secondly, the information obtained in this study was purely from self-report, with no cross-referencing from other family members to establish the veracity of their answers. Future research may benefit from cross-referencing with other family members; though this may not prove particularly productive depending upon the measure examined because emotional, cognitive and behavioural attachment reactions to the experiences felt of having a disabled sibling are entirely subjective. This should be borne in mind, particularly in light of the high propensity to anxious attachment from the SDI cohort, which might mean their willingness to please others overtly overrides their innermost feelings and they can then give biased responses. Further, Hinnen et al (2009) cautioned that adult attachment style may influence the way in which early childhood experiences may be recalled.

An important area for future research has to be to investigate the reasons why there is almost a complete lack of association between the SDI's perception of inconsistent mothering and both anxiety and depression symptomatology, attachment-related anxiety, neuroticism or extraversion; despite the SDI reporting significantly higher levels of all these variables (significantly lower with extraversion) than the control group. Each lack of association found here is completely contrary to past research and if reasons can be established as to why this happens, it should yield some very interesting results; indeed it might prove to be decisive in explaining the increased affective symptomatology of the SDI. I would suggest that semi-

structured interviews with SDI might prove enlightening as they can then feel free to take the conversation where they like but still within a structured basis.

One of the areas that could perhaps be teased out is the potential SDI suppression of emotional responses, particularly towards their parents but always towards their current partners; this is suggested due to the lack of association found between the mothering style and other variables. The lack of association, or potential suppression of feelings might be as an adaptive response, where as a child the SDI might have felt that this suppression of emotion was the best response to his or her parents (Levenson, 1994), in order to preserve the balance of the household if the parents were overtired due to the caretaking demands of the disabled sibling. While emotional suppression can be very effective in the short-term if it is used as a long-term strategy it can be very problematic for the individual because it can either lead to the maintenance or increase of the negative feelings (Campbell-Sills & Barlow, 2007; Gross & John, 2003). When emotional suppression does not change the emotional response in the preferred direction, for instance to alleviate negative affect, the suppression or de-activation of emotional responses can potentially be very damaging for the individual as it can become a breeding ground for affective symptomatology. The concern with the findings from the present study is that if there is suppressed negative emotion towards the mother, then it could continue to cause long-term damage for the SDI. Considerably more research needs to be undertaken into this subject matter with regards to the SDI.

As has been mentioned throughout this study, it would appear to be important to involve the SDI in the early stages of future caregiving plans for the disabled sibling (Heller & Kramer, 2009). If the family was involved in open and honest discussions so that there are no false expectations from either the SDI or the parent, it is imagined that this would potentially alleviate stress from the SDI (Bretherton, 1992; Eisenberg et al. 1998; Heller & Kramer, 1992) as they will then be able to delineate their own responsibilities and plan for the future. An avenue for further research would be to examine those siblings who have been involved in early negotiations regarding their sibling and those who have not. It would then be interesting to ascertain if this difference made any long-term affective difference to the SDI.

The SDI do appear to have heightened affective symptomatology and this is something that has been reported not just in this study but also in meta-analytical studies that have investigated SDI affective symptomatology in childhood (Hastings, 2003; Moore et al.

2002; Rossiter & Sharpe, 2001). Given that none of the variables examined in the current studies fully explain the reasons as to why this is the case, it would be interesting to broaden the scope of the investigation. I would suggest that coping strategies within the SDI are examined; this would enable us to see if the SDI use the more adaptive problem-focused, or the more tenuous emotion-focused strategies (Herman & Tetrick, 2009); the way someone copes with their stress levels can often be indicative of their mental health (Karademas, 2007). Research has also shown that family stressors are negatively related to well-being and can result in dysfunctional coping styles (Karademas, 2007), which can increase vulnerability to depression. This might be highly relevant to the SDI coping strategies and might be useful if interventions or therapies are called for.

Also, levels of self-esteem can be important in emotional well-being (Perkins, Holburn, Deaux, Flory & Vietze, 2002; Schmitz, Kugler & Rollnik, 2003); lowered self-esteem is also associated with insecure attachment and neuroticism and appears to have a principal role in the development and maintenance of depression illnesses (Perkins et al. 2002; Schmitz et al. 2003). Low self-esteem is often associated with a withdrawal from society through feelings of unworthiness or an over-reliance on others to make important decisions. The underlying ethos here would appear to correlate to insecure attachment, which would appear to support the results from the current study. Therefore, it would be interesting to ascertain if the SDI self-esteem levels are on a par with the general population or, given the current research, if they feel that perhaps they are second best.

While romantic relationships have been studied here, it would also be of note to examine perceptions of more general social support. It is an established factor in how well an individual responds to their environment (Naylor & Prescott, 2004). Social support appears to be able to regulate the impact of stressors and can help explain why some individuals can experience adverse events but do not display high levels of distress (Rytsala, Melartin, Leskela-Mielonen, Sokero & Isometsa, 2006). Social support is proposed to be an important factor in the emotional regulation of siblings of the chronically ill (Barlow & Ellard, 2006); it would be interesting to establish if perceived support can help to alleviate some of the affective stressors experienced by adult SDI.

Mastery, or locus of control, is another area that I believe requires a further focus. Limited research has shown that there is an association between externality and insecure attachment styles, particularly preoccupied, and the development of psychopathologies

(Hexel, 2003). A further study also showed that having low levels of mastery was related to depression and proposed that Neuroticism was a mediating influence upon the levels of depression experienced (Clarke, 2004). So, again, while these results appear to be broadly in line with the current findings, further research into mastery will hopefully help to ascertain how much control the SDI perceive to have over their lives or if having a disabled sibling is viewed as an uncontrollable feature that reflects in other areas.

The focus here has been on negative outcomes of the sibling relationship; future research would do well to examine more positive aspects of having a disabled sibling. This could include factors such as compassionate skills, increased empathy and understanding, which could all have a positive impact upon the SDI's overall emotional well-being (Atkins, 1991). This will be an important avenue of exploration as previous research from Heller and Kramer (2009) has indicated the more positive the sibling's opinion, the more likely they are to be involved with their disabled sibling's welfare in the future.

Chapter 5

Conclusions

5.1 Conclusions

The main objective of the study was to establish if anecdotal reporting was correct in indicating poor affective outcomes for SDI groups. The results found here show that the vast majority of the adult SDI group do not have any long-term propensities towards anxiety and depression symptomatology as a result of growing up alongside a disabled sibling. Further, the results clearly show that the majority of the SDI group report that they perceived that their parents treated them warmly, that they are securely attached and are well within the adaptive range for their reported personality traits. However, the results also show that the SDI group do have a significantly higher prevalence towards anxiety and depression symptomatology when compared to the closely matched control group. The reasons behind this are still not entirely clear but, as has been reported by other studies, factors other than just the disability need to be taken into account when trying to explain increased symptomatology (Glenn et al. 2009; Greenberg et al. 2004). These studies, therefore, examined differences between the sibling disability group and the control group, where it was found that the SDI group had significantly higher tendencies to report perceived inconsistent mothering, attachment-related anxiety and increased levels of neuroticism and decreased levels of extraversion than the control group. With the exception of perceived inconsistent mothering, all of these variables partially mediated the relationship between having a disabled sibling and anxiety and depression. Within the specific disability sibling groups it appears that ASD siblings have the highest associative link with anxiety and depression and this is closely followed by PWS siblings. Interestingly, however, the DS sibling group reported similar results to the control group on anxiety and depression. Therefore, evidence from this study has shown some distinct differences not just between the SDI and the control group but also within the different sibling disability groups.

When demographic variables were examined it showed that the independent effects of variables such as gender, age, relationship satisfaction and being younger than the disabled sibling all played a part in SDI affective symptomatology, however, as expected none of the variables examined could fully explain why there were heightened levels of anxiety and depression. However, all these variables were retained as controls for the mediation analyses

as failure to control for them might lead to biased and incorrect results (Goodwin, 2009; Howell, 2009). Interestingly, there was no moderating effect of any of the demographic variables; however, limitations to the use of moderation analysis are included in the Discussion Chapter.

Interestingly, the present research showed the less severe the disability of the sibling, the more predictive it was of depression in the SDI, which went against suggestions put forward by past researchers on children's experiences of being a SDI (Hastings 2003b; Rossiter & Sharpe, 2001); speculative reasons were put forward for why it should differ at adult level, but this should be considered an important area for further attention. Likewise being a primary caregiver for their disabled sibling was associated with an increased propensity towards depression symptoms and this should be investigated more fully in future research in order to ascertain if interventions could help. Understandably, a poor prognosis for the disabled sibling raised anxiety levels, which other than pure concern for their sibling, might also be caused by increased contact with welfare services; this is another area that is worthy of future research.

Positive parental adjustment towards the child with disabilities was predictive of a protective effect towards anxiety and depression as were high levels of current relationship satisfaction. This made intuitive sense as a good role model would teach the young child how to react positively to adverse situations and hopefully reduce the risk of adjustment problems in the SDI (Gold, 1993; Powell & Gallagher, 1993). Interestingly, it was only paternal adjustment that had an ameliorating effect upon depression in this cohort; in most research upon SDI as children, it is the effects of the maternal responses that were most commonly reported but the present results indicate that the role of the father should be investigated further in longitudinal research.

There was no moderating effect of gender upon having a disabled sibling and anxiety or depression, which indicates that the affective disorders correspond equally across both groups; however, the gender of the participant did have an effect on depression and anxiety symptomatology. Females from both groups reported higher affective indicators than their male counterparts. This reflects general research into gender differences (Nolen-Hoeksema, 2001; Parker & Hadzi-Pavlovic, 2001; WHO, 2010) but it is also suggested that the higher prevalence of SDI females with anxious and depression symptomatology might be exacerbated by the increased caretaking role they were probably obliged to undertake in

childhood (Moore et al. 2002; Powell & Gallagher, 1993; Turnbull & Turnbull, 1990) and the continued responsibility towards their disabled sibling into adulthood (Hodapp & Urbano, 2007; Orsmond & Seltzer, 2007b). This is surely an area where targeted intervention would help; whether it would be through making the parents more aware of the increased burden placed upon their daughter and the long-term effects that this can have, or trying to get the female SDI to put preventative strategies in place, so that something can protect them.

The trend towards increased SDI male depression symptomatology could be due to the same reasons behind the SDI female affective prevalence, albeit to a lesser extent. What is not clear is if the affective levels are decreased in the male SDI in comparison to female SDI as a reflection of the normative male experience or if it is due to the earlier and current experiences with their disabled sibling where they are not quite as involved as their sisters with the care of their disabled sibling (Orsmond & Seltzer, 2007b) and if this offers a protective element. However, it does not appear to be sufficient to shield them from higher levels of affective issues than the general male population.

Relationship satisfaction, as an independent effect, was seen to have a significant ameliorating effect upon both affective disorders; however, again no moderating effect was found. The SDI relationships tended to be longstanding and high in satisfaction levels, which were roughly equivalent to the control group. It was a very positive indicator to see high levels of satisfaction within the SDI group as this area of social support can increase emotional well-being within the individual (Amato & Cheadle, 2005, Collins et al. 2002; Cooper, 2002; Davis et al. 1998). Relationship satisfaction in the SDI group had a particular protective effect against anxiety but no significant associative effect with depression. Given that relationship satisfaction in both groups was negatively associated with attachment-related anxiety and neuroticism, which in turn have negative associations with anxiety and depression (Bowlby, 1973, 1980, 1982; Hutchinson & Williams, 2007; Jylhä & Isometsä, 2006; Lönnqvist et al. 2009; Mikulincer & Shaver, 2007; Watson et al. 2005); the topic of relationship satisfaction and partner choice would be a helpful area for any clinical practitioner to explore.

Whether the sibling was born before or after their brother or sibling with disabilities had mixed results. There was a definite attachment pattern, with those born after the disabled sibling reporting significantly higher preoccupied attachment and those born before reporting significantly higher secure attachment. However, there was no difference due to birth order

for any of the personality traits or for perceived inconsistent mothering. It is difficult to draw an overall conclusion from this, which reflects previous research (Crnic et al, 1983; Levy-Wasser & Katz, 2004; Stoneman et al. 1991); due to the effect size being small for the attachment categories, it might be a finding that is specific to this cohort but further investigation might inform the results. If there is a pronounced difference due to birth order this might help future interventions or therapies. It might be that early targeted intervention with support groups is necessary to fully support and educate the families, especially the siblings, at the earliest possible stage, in order to hopefully ease future affective issues (Carpenter, 2000; Dodd, 2004; Hastings, 2003b; Meadan et al. 2010; Naylor & Prescott, 2004). This would be in line with the suggestions made by many previous researchers into adult siblings as per the Davys et al (2011) literature review.

Speculative reasons for the finding are raised whereby the SDI, at some stage along their developmental route, recognise and then intellectualise that the issues they face regarding the disabled sibling are nobody's fault. Therefore, if no blame can be apportioned, they intrinsically learn to live with the situation and suppress emotion, which allows them to cope with the situation. The SDI most probably wishes the best for the whole family and, therefore, in order to live harmoniously their own needs are then placed at second best. This is evidenced through the lack of association with the perceived inconsistent mothering styles but still recognising increased levels of attachment-related anxiety, neuroticism and decreased levels of extraversion. It is suggested that despite the SDI activating cognitive control over what is happening, the underlying emotional issues cannot be overcome and are thus supressed. Consequently, the adult SDI may have intellectualised the problems that their parents faced when their disabled sibling was growing up and have subsequently de-activated all associations with anything negative to do with their mother as an adult protective response.

Another point of interest when looking at SDI familial relationships is the similar findings with regards to associations with parents. Parental divorce is regarded as being a stressful time in a child's life (Amato & Cheadle, 2005); however, there was no association between the absent parent's contact after the divorce and adult anxiety and depression in the SDI; this is in contrast to the control group where absent parent contact after the divorce is significantly associated with decreased anxiety and depression symptomatology. This would suggest that the SDI have suppressed all affective matters relating to their parents, which includes the good points along with the bad. This lack of SDI association of parental care

with adult affective issues would not appear to be clinically healthy and if an SDI should present for clinical purposes, a physician would do well to address the aetiological causes for this.

The higher levels of attachment-related anxiety reported by the SDI and the significant mediating effect of this variable in explaining the link between having a disabled sibling and both anxiety and depression symptomatology is indicative that the SDI have a low model of self, which usually means that they do not feel as worthy as others and that this can help to explain their route to the affective disorders. What is not clear from this research is whether the attachment-related anxiety is a residual effect from childhood or if it is a product of something happening within their adult lives. It might have been that in childhood the SDI learned through their disabled sibling that relationships are about giving and that they are not necessarily reciprocal. This relationship style might have been retained into adulthood, whereby they still put others before themselves. This again implies a low model of self and a high model of others, which is indicative of attachment-related anxiety.

It could be that the increased rates of attachment-related anxiety could have little to do with the prototypical links with the maternal behaviour in their childhood but are developed or sustained through current issues involving their disabled sibling; given that it was adult attachment style that was being examined this could be a realistic expectation. The feelings causing the insecurity could be either guilt or feeling overburdened in respect of responsibilities to their disabled sibling (Mikulincer & Shaver, 2007; Siegel et al. 2001). However, attachment-related anxiety usually develops as a result of inconsistent parenting (Bowlby, 1973, 1980, 1982) and the insecure trajectory deepens the longer the situation occurs (Bowlby, 1982; Hamilton, 2000). Therefore, it is unusual to find that despite the higher reported levels of inconsistent parenting and higher levels of attachment-related anxiety that no SDI association could be established between the two and consequently further research into this area was suggested.

The increased prevalence of higher levels of neuroticism and lower levels of extraversion in the SDI is a cause for concern and it was shown in this study that they mediated the relationship between having a disabled sibling and anxiety and depression. They are often considered to be maladaptive personality traits (Watson et al. 2005) and are an established cause in the development and maintenance of affective disorders (Hutchinson & Williams, 2007; Spinhoven et al. 2011; Steunenberg et al. 2009a, b; Watson et al. 2005).

Increased neuroticism is often associated with higher levels of negative emotionality and an inability to adaptively cope with stressful situations (Jylhä & Isometsä, 2006), whereas, lower levels of extraversion are often associated with not feeling comfortable in social situations, emotional withdrawal and shyness (Muris et al. 2009; Shiner & Caspi, 2003). These are all factors that are contributory in sustaining anxiety and depression.

While it is suggested that there is a degree of plasticity within personality traits and that extraversion and neuroticism decline with age (e.g., Gow et al. 2005); other research argues that neuroticism and extraversion are classed as stable personality traits, whereby they remain fairly consistent over time (McCrae, 2002; McCrae et al. 2000). If heightened neuroticism and low extraversion are suspected of being stable within an individual, and my results show that SDI are more vulnerable towards these traits, it should be remembered that the traits are indicators of increased affective disorders (Clark et al. 2005) It can, therefore be argued that an insignificant trigger, such as daily hassles (Hutchinson & Williams, 2007), could produce a negative affect that would leave the SDI at a higher risk of vulnerability to anxiety and /or depression in comparison to a control group. Therefore, the potential for the SDI developing and suffering from these affective disorders appears to be much greater.

Similarly to attachment-related anxiety, the aetiological reasons for the development of the increased propensity of the SDI to report increased neuroticism levels and decreased extraversion levels was not investigated in these studies and a study of a longitudinal design would be helpful in trying to explain more precise causes. However, once again, speculative reasons were given as to the prevalence of these personality traits. I suspect that the longevity of the recurring issues, such as behavioural or chronic health problems of the disabled sibling, might be influential in the maintenance of the traits (Moore et al. 2002; Rossiter & Sharpe, 2001; Spinhoven et al. 2011) as these issues fits in with the notion that adverse events in childhood would lead to an aggregated propensity towards negative affect throughout the lifespan (Rosenman & Rogers, 2006). Likewise, Spinhoven et al (2011) found that negative life events predicted anxiety and depression over a 12 month period and that the personality traits of neuroticism and extraversion played a small but significant part in this. Many adult siblings maintain contact with their sibling after they have left home (Hodapp & Urbano, 2007; Orsmond & Seltzer, 2007b, Lounds-Taylor et al. 2008); however, Lounds-Taylor et al (2008, p. 912) describe it as an ‘obligatory relationship’, where they feel that family loyalty makes them duty-bound to visit their sibling. This scenario does suggest that low extraversion and high neuroticism are prevalent within the SDI; it does also suggest how neuroticism and

extraversion could mediate the route between having a disabled sibling and anxiety and /or depression, which is what my study found. The Lounds-Taylor et al scenario would also suggest high levels of conscientiousness and agreeableness but these variables were not found to be significant within my findings.

Openness was not shown to have any significant mediating effect between having a disabled sibling and anxiety or depression; however, a trend was indicated for an ameliorating effect upon depression. The SDI group also showed significantly higher levels of openness than the control group, which was expected due to some of the more unusual circumstances that they might have learned to tolerate when growing up alongside their disabled sibling. Interestingly, however, the SDI reported significantly higher academic achievements than the control group, which also showed a significant independent effect in ameliorating depression symptomatology and so it might be that the intellectual aspect of the openness trait would be the one to focus on when trying to understand the SDI's affective responses.

The results from the study indicate the importance of recognising that different disability types will often result in different affective outcomes, not just for the disabled individual but for the whole family. This recognition would be especially important if a SDI required clinical help and so different aetiological causes might need to be examined and interventions can then be directed more appropriately.

The findings from this study regarding the effect that different disability types indicate that DS siblings fare much better than those whose siblings have ASD; this is line with previous research (Hastings, 2007; Hodapp & Urbano, 2007; Orsmond & Seltzer, 2007a, b). Indeed, the DS sibling outcomes are broadly similar to the control group. When the groups were examined using the established measures, the results showed no significant overall differences between the disability groups and the control group for perceived inconsistent mothering, neuroticism or extraversion; the only significant difference between the groups was for attachment-related anxiety, whereby the ASD sibling group reported significantly higher levels than the control group. The overall prevalence for poorer outcomes for the ASD sibling is, perhaps, not surprising; ASD individuals tend to be less socially reciprocal than DS siblings, can have maladaptive behaviours and can also self-harm (Dimitropoulos & Schultz, 2007; Orsmond & Seltzer, 2007a, b; Veltman et al. 2004), all of these behaviours were likely to be highly stressful to the siblings as they were growing up,

which might have triggered the onset of anxiety and depression symptomatology. Or it might be due to current issues such as the responsibility of the long-term welfare of their disabled sibling and feelings of pessimism regarding their sibling's future (Orsmond & Seltzer, 2007a) that might have initiated the onset of the symptomatology. The current research could only identify the differences but could not fully elicit the reasons for them; further research is required to find out more in-depth answers.

A novel aspect of this research is that it also included a PWS sibling group. There are a number of interesting similarities between the PWS and ASD siblings, particularly the extremely similar anxiety and depression symptomatology scoring. Given the many behavioural similarities between PWS and ASD individuals (Dimitropoulos & Schultz, 2007; Veltman et al. 2004) it is suggested that the developmental course of the disabilities have created the same affective outcomes in their siblings. This might help any future clinician to begin to understand the aetiological root of the issues and it also might give direction to prophylactic interventions, in knowing where to begin to target therapies (Hastings, 2007; Orsmond & Seltzer, 2007b).

It should be considered that, particularly in the case of disabilities such as ASD, the specific affective sibling outcomes might be due to the SDI concern with the heritability of the disorders. There is a common consensus that there is a strong genetic component to ASD and siblings might be at risk of some of the phenotypic characteristics of the condition (Orsmond & Seltzer, 2007b). PWS siblings might not share the same absolute concerns regarding heritability but are likely aware of the approximately 2% possibility of a genetic mutation being passed on from parent to child (Prader-Willi Syndrome Association, USA, 2011). DS siblings are aware that the DS condition is due to a chromosomal abnormality most often associated with maternal age and not genetic abnormalities (www.downs-syndrome.org.uk/information/html). This could help to explain why the siblings of DS individuals experience fewer affective disorders than those with PWS siblings and, in turn, ASD siblings. ASD siblings and, to a lesser extent, PWS siblings, might live with the concern that they could potentially pass on a genetic disorder to their own offspring. This could cause them considerable distress that they might not have had to live with other than for the fact that having a sibling with disabilities has made them aware of the possibilities. This is an indirect effect of growing up alongside a disabled sibling and so it is not the sibling behaviours per se that are directly contributable to increased levels of affective symptomatology within the ASD and PWS siblings.

The impact of the different disability types could influence the future care of disabled siblings. The inter-relationships between the siblings should be studied to a greater extent, in order to try to establish what particular characteristics encourage the sibling to care for their disabled sibling. By establishing certain factors, it might be possible in a clinical setting to get the sibling to focus on positive aspects of the disabled sibling's characteristics and caregiving, which might enhance their relationship (Greenberg et al. 2004; Hastings, 2003b; Heller & Kramer, 2009). The focus on enhancing their own positive affect towards their disabled sibling might also be extremely beneficial (Greenberg et al. 2004; Heller & Kramer, 2009). This resilience factor has been shown to be advantageous in emotional responses to stress, allowing for easier emotional recovery especially at times categorised by heightened stress levels (Ong, Bergeman, Bisconti & Wallace, 2006).

This build-up of resilience might be particularly valid if it comes to encouraging involvement of the sibling in the direct or indirect caregiving of their disabled sibling. The sibling might have a reluctance to include the disabled sibling in family activities of their own; particularly if they remember distressing or embarrassing encounters that they had to overcome as children, and may not wish for their own children to have to experience these. This might be especially true for ASD siblings, who might remember temper tantrums, problems with poor social interactions and negative reactions to stressful events (National Autistic Society, 2010). And to some extent, siblings of PWS might have experienced similar issues (Dimitropoulos & Schultz, 2007; Veltman et al. 2004). This could cause additional affective issues for these adult siblings as they struggle to balance the needs of their family with the needs of their disabled sibling. In contrast, the inter-relationship with a DS sibling, though still demanding, could be seen as considerably more socially interactive (www.downs-syndrome.org.uk/information/html) and, consequently, DS individuals are possibly more likely to be included on family occasions, thus reducing the potential internal affective conflict of the DS sibling as reflected in the results of my study. Research then needs to focus on identifying which typical characteristics of the conditions relate to specific reactions from siblings and from others.

The results of the study demonstrated the significant detrimental effect of high neuroticism levels on affective well-being, particularly anxiety symptomatology, for the ASD and PWS siblings, not just in the short-term but also the longer-term implications must be borne in mind. Likewise, but to a lesser extent, lower levels of extraversion are associated with depression, again for the ASD and PWS sibling groups. The pattern with affective

disorders is typical of normative studies (Watson et al. 2005) and can also be seen in the control group; but not with the same significance as to the disability sibling groups. The siblings might have been unduly affected due to the lifelong event of living alongside a person with disabilities, with the potential additional stressors that could be prevalent, which may have had a lasting impact on the sibling personality traits. This would be in contrast to more sporadic events that have little lasting impact upon personality (Spinhoven et al. 2011). However, the aetiological reasons for the development of the maladaptive personality traits should be further investigated, possibly through actually asking the siblings what they think they require in terms of support (Meadan et al. 2010); the causes of the prevalence towards the traits could then perhaps be halted through a prophylactic intervention programme (Hastings, 2007). Or, recognition of them could prove useful in a clinical setting, where help could be targeted to try to alleviate symptoms (Jylhä & Isometsä, 2006; Widiger & Anderson, 2003).

The relationship between attachment-related anxiety and anxiety and depression symptomatology has been established through previous research (Mikulincer & Shaver, 2007; Murphy & Bates, 2007; Reis & Grenyer, 2004). Attachment styles are generally not produced consciously but rather results from intrinsic reactions to the subliminal interpretations of how someone feels that they have been treated by an important other. It could, however, be that the siblings have intellectualised the parental position as they were growing up and now understand the difficult position that the parent was in; sometimes the needs of the disabled child had to be exclusively met in order for the whole family to run cohesively. It would perhaps then be wise for future research to ascertain if perceived inconsistent mothering acts as a mediator between having a sibling with ASD and anxiety symptomatology; this is due to having a child with ASD being regarded as one of the most challenging on the disability spectrum (Orsmond & Seltzer, 2007b; Osborne & Reed, 2010). The mother would surely often be distracted by her child with ASD, possibly leaving her other children feeling somewhat neglected. However, despite the understanding and the lack of blame that comes with adulthood, the intrinsic feelings of perceiving that their needs were placed behind those of their disabled sibling, could mean that attachment-related anxiety feelings act as a mediator for affective disorders (Reis & Grenyer, 2004; Mikulincer & Shaver, 2007).

An interesting finding from this study is that the younger siblings of ASD and DS siblings are more likely to report heightened anxiety than those siblings who are older than

their disabled sibling. However, younger PWS siblings did not report heightened anxiety levels but were more likely to report depression symptomatology than siblings who are older; this was not significant in ASD or DS siblings. Due to the nature of the disabilities, whereby PWS is detectable from birth whereas ASD often first shows at approximately two years (Baird, Cass & Slonims, 2003), this could suggest that there is an affective impact upon siblings born just after the PWS sibling, as they are born into a house that is aware of and living with the new-found knowledge of a serious disability. The parents of the ASD child might be completely unaware of their ASD child's disability throughout the early stages and therefore subsequent children that are born would be treated as belonging to a normally functioning family. However, despite these postulated scenarios, the younger siblings do appear more vulnerable than older siblings and this might imply the seriousness of the very early years in setting a trajectory for vulnerability to affective disorders, and it is one that clinicians and parents should be aware of, if future research confirms these findings.

5.2: Summary

To conclude, this study set out to explore if the anxiety and depression symptomatology outcomes for adult SDI differed from the general population. It, thereafter, sought to ascertain if there were differences between the SDI and the general population on recalled parenting styles, attachment styles and personality traits that are known to be influential in affective outcomes. Mediating or moderating influences of the theories were sought that could help to explain why and what could be behind having a disabled sibling and the significantly increased propensity towards anxiety and depression symptomatology when compared to the control group; it was, however, beyond the scope of the study to establish the root causes of the tested theories and much further investigation is required into this. The results indicate that the majority of siblings are not in the clinical realms for anxiety and depression; however, there are enough consistent pointers in a percentage of the SDI group towards decreased levels of emotional well-being to raise cause for concern.

The study of the affective outcomes of adult SDI is a relatively new area and consequently there has been limited research to date. I am not aware of any research that has examined SDI anxiety and depression in association with perceived parenting styles, attachment styles and personality traits. Attachment-related anxiety, neuroticism and extraversion all mediated the path between having a disabled sibling and anxiety and

depression. It is suggested that these factors should be taken into consideration if interventions or clinical therapy is required. The factor that goes against previous research is perceived inconsistent mothering, which not only did not explain the path between the variables but there was little associative effect between the SDI perceived mothering style and the rest of the variables under examination. I suggest that this warrants further research as it might help to explain the increased symptomatology of the SDI.

Whatever the aetiology of the increased SDI incidence of this form of insecure attachment-related anxiety, previous research has made clear the links between attachment-related anxiety and heightened reporting of anxiety and depression symptomatology (Brennan & Shaver, 1998; Mikulincer & Shaver, 2007). These findings will therefore be very useful if a SDI should need to present in a clinical setting, whereby perhaps a clinician could draw out the attachment issues and attempt to divert the individual towards a more secure trajectory (Berant & Obegi, 2009; Bifulco et al. 2006, Hinnen et al. 2009; Mikulincer & Shaver, 2007; Shaver & Mikulincer, 2008). Research should focus on potential clinical interventions associated with attachment-related anxiety when presented with individuals whose siblings had different disability types, in order to be able to fine-tune relevant therapies (McBride & Atkinson, 2009). Clinicians should also be aware of the possible unintended ambivalent parental behaviour experienced, due to parenting another child with disabilities (Berant & Obegi, 2009). The inter-relationship between the siblings should also be addressed to ascertain if this had an effect on adult attachment styles. The ECR attachment questionnaire used in my study was designed to elicit answers regarding adult attachment to others whom the respondent has a romantic relationship with (Brennan et al. 1998) but I would suggest that future research focuses on an attachment measure that will be more specific to a sibling relationship. The clinician should also focus on particular personality traits that might be witnessed in the SDI, as has been demonstrated in this study there is a higher prevalence of heightened levels of neuroticism and decreased levels of extraversion in the SDI. Previous research has noted the high association of these levels of personality traits to anxiety and depression symptomatology (Watson et al. 2005).

Previous research has indicated that ASD siblings have more emotional problems than DS siblings (Hodapp & Urbano, 2007; Orsmond & Seltzer, 2007a); this was supported by my research, with ASD siblings reporting significantly higher levels of anxiety and depression symptomatology when compared to DS siblings. As a novel concept, siblings of PWS were included and their affective outcomes were very similar to ASD siblings. The behavioural

patterns of the two disabilities are similar and it is suggested that early recognition and intervention that specifically targets the problems should be made available in these instances in order to alleviate future problems. It is necessary that research into SDI affective well-being continues as this is one of the first generations that may well assume the long-term responsibility for their disabled siblings and they need to be psychologically fit to be able to do so.

What is not clear from my study is if increased SDI affective vulnerability is as a result of experiencing stressful events regarding their disabled sibling when they were young, which might have left them with a lifelong vulnerability towards these affective disorders (Allen & Rapee, 2009; Spinhoven et al. 2010). Or, conversely, if it is current pressures regarding their disabled siblings, such as planning for their future caretaking needs that are creating their increased vulnerability. It might be additionally relevant as the SDI participants in this study were primarily from the so called 'sandwich generation', whereby they possibly expect at some stage to have responsibility not just for their own children but for their parents too; this could mean that, for some, the additional responsibility that they might feel they might have to undertake for their disabled sibling, may be a little overwhelming (Hodapp & Urbano, 2007). This should be considered an important point for interventions, and particularly perhaps should influence government policy, who it is suggested should possibly be introducing more easily accessible care packages for adults with disabilities.

Without overburdening parents of a disabled child, at an already stressful time, it is suggested that perhaps an informal, but obligatory, session on the recognition of the needs of other children that they might have, might help to prevent or alleviate potential future problems. It is also suggested that the earlier the interventions are put in place, if necessary, the more beneficial it would be for the individual in order that they might re-direct their path to a secure attachment trajectory prior to insecure attachment habits or maladaptive personality traits becoming embedded (Bowlby, 1982). This might mean open and honest, supportive talks with siblings of disabled individuals when they are still relatively young, so that they could realize what the expectations required from them are, with regards to their disabled sibling. Honesty about the future and participation in negotiations regarding plans for the disabled sibling's future could alleviate the stress of the unknown for the SDI (Bretherton, 1992; Heller & Kramer, 2009).

6.0. References

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APPENDIX A: Questionnaire for Pilot study

PART 1 – BACKGROUND INFORMATION

Are you male or female? **Male [ ] Female [ ]**

What age are you? **[ ]**

Ethnic background? **British [ ] Irish [ ] other European [ ]**

American [ ] Afro/Caribbean [ ]

Asian [ ] New World [ ] other [ ]

Marital status? **Single [ ] Married [ ] Separated [ ]**

Divorced [ ] Co-habiting [ ] Widow/er [ ]

How long in current relationship? **No current relationship [ ] Less than 3 months [ ]**

3 - 6 months [ ] 6 months – 2 years [ ]

2 – 5 years [ ] 5 + years [ ]

How long in previous relationship? **_____**

How do you rate your current relationship? **[ ]**

Where, 1 means extremely unsatisfactory

2 means unsatisfactory

3 means satisfactory

4 means extremely satisfactory

Are you working at the moment? Yes/ No*

If so, what as? **_____**

What is your annual income? Under £10,000 [ ] £10,001 – 15,000 [ ]

£15,001 – 20,000 [ ] £20,001 – 30,000 [ ] £30,001 – 45,000 [ ]
£ 45,001 – 70,000 [ ] £70,001 + [ ]

What educational qualifications did you gain? None [ ] Technical [ ]GCSE [ ]

'A' levels [ ] Degree [ ] Postgrad [ ]

What was the highest educational qualification your mother gained? _____

What was the highest educational qualification your father gained? _____

Which religion are you? _____

Do you attend religious worship regularly? Yes / No*

Are your parents divorced? Yes / No*

If yes, what age were you when they divorced? _____

Did the absent parent maintain regular contact with you? Yes / No*

Do you have any current medically diagnosed illness? Yes / No*

If yes, what is it? _____

How many brothers and sisters (siblings) do you have? [ ]

In which order were you born? *ie.,1st, 2nd, 3rd, 4th,etc.* [ ]

Had you a sibling with a disability that required increased parental involvement? Yes/No*

*** Please delete as appropriate**

If you have answered 'yes' to this question please continue to answer the rest of the questions.

If not, please move on to the next section (Part 2).

What is the current age of your disabled sibling? (If deceased, please put age of death) [ ]

How is the severity of the disability classed? *Where, 1 means mild* [ ]

2 means moderate

3 means severe

4 means profound

What was the age of your sibling when the disability was first suspected? [ ]

Has your sibling been medically diagnosed? Yes [ ] No [ ]

If so, what has your sibling been diagnosed with? _____

What was the age of your sibling when the disability was first diagnosed? [ ]

Is there a prognosis? Yes [ ] No [ ]

If so, what is the prognosis (expected long-term outcome?

_____

In which order was your disabled sibling born? *ie., 1st, 2nd, 3rd, 4th, etc* **[ ]**

Is your disabled sibling living with you? Yes [ ] No [ ]

If so, are you the primary (main) carer for your disabled sibling Yes [ ] No [ ]

How well do you think your mother adjusted to having a disabled child? [ ]

Where, 1 means very well - disability incorporated into normal family life

2 means quite well – usually coped with disability but periods of difficulty coping

3 means average – family life usually functional, but constant ups and downs re disability

4 means quite poorly – generally overwhelmed by disability, but controlled

5 means very poorly – family life completely revolved around disability

6 means extremely poorly – acted as if disability was inconvenience and did not exist

How well do you think your father adjusted to having a disabled child? [ ]

Please use 1- 6 scoring scale, as above.

PART 2

For <u>each</u> of the three descriptions below please indicate how far you feel each describes your mother's behaviour towards you when you were a child, by putting a number between 1 and 7 in the box,

where, 1 means strongly disagree, 2 means disagree, 3 means slightly disagree, 4 means neither agree nor disagree, 5 means slightly agree, 6 means agree, 7 means strongly agree

She was generally warm and responsive; she was good at knowing when to be supportive and when to let me operate on my own; our relationship was almost always comfortable, and I have no major reservations or complaints about it.	
She was fairly cold and distant, or rejecting, not very responsive; I wasn't her highest priority, her concerns were often elsewhere; it's possible that she would just as soon not have had me.	
She was noticeably inconsistent in her reactions to me, sometimes warm and sometimes not; she had her own agendas which sometimes got in the way of her receptiveness and responsiveness to my needs; she definitely loved me but didn't always show it in the best way.	

For <u>each</u> of the three descriptions below please indicate how far you feel each describes your father's behaviour towards you when you were a child, by putting a number between 1 and 7 in the box

where, 1 means strongly disagree, 2 means disagree, 3 means slightly disagree, 4 means neither agree nor disagree, 5 means slightly agree, 6 means agree, 7 means strongly agree

He was generally warm and responsive; he was good at knowing when to be supportive and when to let me operate on my own; our relationship was almost always comfortable, and I have no major reservations or complaints about it.	
He was fairly cold and distant, or rejecting, not very responsive; I wasn't his highest priority, his concerns were often elsewhere; it's possible that he would just as soon not have had me.	
He was noticeably inconsistent in his reactions to me, sometimes warm and sometimes not; he had his own agendas which sometimes got in the way of his receptiveness and responsiveness to my needs; he definitely loved me but didn't always show it in the best way.	

(DPCS, Hazen & Shaver, 1986)

Please try to answer the following questions as honestly as possible. It will be useful if you can describe yourself as you feel you compare to others of the same sex and approximate age group. Please circle the number you think is most appropriate.

Items	**Very Inaccurate**		**Neutral**		**Very Accurate**
1. Am the life of the party.	**1**	**2**	**3**	**4**	**5**
2. Feel little concern for others.	**1**	**2**	**3**	**4**	**5**
3. Am always prepared.	**1**	**2**	**3**	**4**	**5**
4. Get stressed out easily	**1**	**2**	**3**	**4**	**5**
5. Have a rich vocabulary.	**1**	**2**	**3**	**4**	**5**
6. Don't talk a lot.	**1**	**2**	**3**	**4**	**5**
7. Am interested in people.	**1**	**2**	**3**	**4**	**5**
8. Leave my belongings around.	**1**	**2**	**3**	**4**	**5**
9. Am relaxed most of the time.	**1**	**2**	**3**	**4**	**5**
10. Have difficulty understanding abstract ideas.	**1**	**2**	**3**	**4**	**5**
11. Feel comfortable around people.	**1**	**2**	**3**	**4**	**5**
12. Insult people.	**1**	**2**	**3**	**4**	**5**
13. Pay attention to details.	**1**	**2**	**3**	**4**	**5**
14. Worry about things.	**1**	**2**	**3**	**4**	**5**
15. Have a vivid imagination.	**1**	**2**	**3**	**4**	**5**
16. Keep in the background.	**1**	**2**	**3**	**4**	**5**

17. Sympathise with others' feelings.	**1**	**2**	**3**	**4**	**5**
18. Make a mess of things.	**1**	**2**	**3**	**4**	**5**
19. Seldom feel blue.	**1**	**2**	**3**	**4**	**5**
20. Am not interested in abstract ideas.	**1**	**2**	**3**	**4**	**5**
21. Start conversations.	**1**	**2**	**3**	**4**	**5**
22. Am not interested in other people's problems.	**1**	**2**	**3**	**4**	**5**
23. Get chores done right away.	**1**	**2**	**3**	**4**	**5**
24. Am easily disturbed.	**1**	**2**	**3**	**4**	**5**
25. Have excellent ideas.	**1**	**2**	**3**	**4**	**5**
26. Have little to say.	**1**	**2**	**3**	**4**	**5**
27. Have a soft heart.	**1**	**2**	**3**	**4**	**5**
28. Often forget to put things back in their proper place.	**1**	**2**	**3**	**4**	**5**
29. Get upset easily.	**1**	**2**	**3**	**4**	**5**
30. Do not have a good imagination.	**1**	**2**	**3**	**4**	**5**
31. Talk to a lot of different people at parties.	**1**	**2**	**3**	**4**	**5**
32. Am not really interested in others.	**1**	**2**	**3**	**4**	**5**
33. Like order.	**1**	**2**	**3**	**4**	**5**
34. Change my mood a lot.	**1**	**2**	**3**	**4**	**5**
35. Am quick to understand things.	**1**	**2**	**3**	**4**	**5**
36. Don't like to draw attention to myself.	**1**	**2**	**3**	**4**	**5**
37. Take time out for others.	**1**	**2**	**3**	**4**	**5**

38. Shirk my duties.	**1**	**2**	**3**	**4**	**5**
39. Have frequent mood swings.	**1**	**2**	**3**	**4**	**5**
40. Use difficult words.	**1**	**2**	**3**	**4**	**5**
41. Don't mind being the centre of attention.	**1**	**2**	**3**	**4**	**5**
42. Feel others' emotions.	**1**	**2**	**3**	**4**	**5**
43. Follow a schedule.	**1**	**2**	**3**	**4**	**5**
44. Get irritated easily.	**1**	**2**	**3**	**4**	**5**
45. Spend time reflecting on things.	**1**	**2**	**3**	**4**	**5**
46. Am quiet around strangers.	**1**	**2**	**3**	**4**	**5**
47. Make people feel at ease.	**1**	**2**	**3**	**4**	**5**
48. Am exacting in my work.	**1**	**2**	**3**	**4**	**5**
49. Often feel blue.	**1**	**2**	**3**	**4**	**5**
50. am full of ideas.	**1**	**2**	**3**	**4**	**5**

(IPIP, Goldberg, 1999)

The following statements concern how you feel in romantic relationships. We are interested in how you generally experience relationships, not just in what is happening in a current relationship. Respond to each statement by circling how much you agree or disagree with it.

Items	Disagree Strongly			Neutral			Agree Strongly
1. I prefer not to show a partner how I feel deep down.	1	2	3	4	5	6	7
2. I worry about being abandoned.	1	2	3	4	5	6	7
3. I am very comfortable being close to romantic partners	1	2	3	4	5	6	7
4. I worry a lot about my relationships	1	2	3	4	5	6	7
5. Just when my partner starts to get close to me I find myself pulling away.	1	2	3	4	5	6	7
6. I worry that romantic partners won't care about me as much as I care about them	1	2	3	4	5	6	7
7. I get uncomfortable when a romantic partner wants to be very close.	1	2	3	4	5	6	7
8. I worry a fair amount about losing my partner.	1	2	3	4	5	6	7
9. I don't feel comfortable opening up to romantic partners.	1	2	3	4	5	6	7
10. I often wish that my partner's feelings for me were as strong as my feelings for him/her.	1	2	3	4	5	6	7

11. I want to get close to my partner, but I keep pulling back.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
12. I often want to merge completely with romantic partners, and this sometimes scares them away.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
13. I am nervous when partners get too close to me.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
14. I worry about being alone	**1**	**2**	**3**	**4**	**5**	**6**	**7**
15. I feel comfortable sharing my private thoughts and feelings with my partner.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
16. My desire to be very close sometimes scares people away.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
17. I try to avoid getting too close to my partner.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
18. I need a lot of reassurance that I am loved by my partner.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
19. I find it relatively easy to get close to my partner.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
20. Sometimes I feel that I force my partners to show more feeling, more commitment.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
21. I find it difficult to allow myself to depend on romantic partners.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
22. I do not often worry about being abandoned.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
23. I prefer not to be too close to romantic	**1**	**2**	**3**	**4**	**5**	**6**	**7**

partners.							
24. If I can't get my partner to show interest in me, I get upset or angry.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
25. I tell my partner just about everything.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
26. I find that my partner(s) don't want to get as close as I would like.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
27. I usually discuss my problems and concerns with my partner.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
28. When I'm not involved in a relationship, I feel somewhat anxious and insecure	**1**	**2**	**3**	**4**	**5**	**6**	**7**
29. I feel comfortable depending on romantic partners.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
30. I get frustrated when my partner is not around as much as I would like.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
31. I don't mind asking romantic partners for comfort, advice, or help.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
32. I get frustrated if romantic partners are not available when I need them.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
33. It helps to turn to my romantic partner in times of need.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
34. When romantic partners disapprove of me, I feel really bad about myself.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
35. I turn to my partner for many things, including comfort and reassurance.	**1**	**2**	**3**	**4**	**5**	**6**	**7**

36. I resent it when my partner spends time away from me.	**1**	**2**	**3**	**4**	**5**	**6**	**7**

(ECR, Brennan, Clark & Shaver, 1998)

Below is a list of statements indicating how much you feel that you can rely on others for support. Please answer each question by circling the number you feel is most accurate.

Items	**Disagree Strongly**			**Neutral**			**Agree Strongly**
1. There is a special person who is around when I am in need.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
2. There is a special person with whom I can share my joys and sorrows.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
3. My family really tries to help me.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
4. I get the emotional support and help I need from my family.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
5. I have a special person who is a great source of comfort to me.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
6. My friends really try to help me.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
7. I can count on my friends when things go wrong.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
8. I can talk about my problems with my family.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
9. I have friends with whom I can share my joys and sorrows.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
10. There is a special person in my life who cares about my feelings.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
11. My family is willing to help me make decisions.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
12. I can talk about my problems with my friends.	**1**	**2**	**3**	**4**	**5**	**6**	**7**

(MSPSS, Zimet, Dahlem, Zimet & Falrley, 1988)

This section asks about the VIEWS people hold about THEMSELVES. please reply to all the items. Circle your response choice for each item on the table:

Items	**Disagree Strongly**	**Disagree**	**Agree**	**Agree Strongly**
1. On the whole I am satisfied with myself.	**1**	**2**	**3**	**4**
2. At times, I think I am no good at all.	**1**	**2**	**3**	**4**
3. I feel that I have a number of good qualities.	**1**	**2**	**3**	**4**
4. I am able to do things as well as most other people.	**1**	**2**	**3**	**4**
5. I feel I do not have much to be proud of.	**1**	**2**	**3**	**4**
6. I certainly feel useless at times.	**1**	**2**	**3**	**4**
7. I feel that I am a person of worth, at least on an equal plane with others.	**1**	**2**	**3**	**4**
8. I wish I could have more respect for myself.	**1**	**2**	**3**	**4**
9. All in all, I am inclined to feel that I am a failure.	**1**	**2**	**3**	**4**
10, I take a positive attitude towards myself.	**1**	**2**	**3**	**4**

(RSES, Rosenberg, 1965)

The questions below are concerned with how you GENERALLY cope with problems in YOUR LIFE. Please circle your response choice for each item in the table below.

Items	**Never**	**rarely**	**some-times**	**often**	**always**
1. I try to change the situation to get what I want.	**1**	**2**	**3**	**4**	**5**
2. I make an effort to change my expectations.	**1**	**2**	**3**	**4**	**5**
3. I tell myself the problem was unimportant.	**1**	**2**	**3**	**4**	**5**
4. I try to keep myself from thinking about the problem.	**1**	**2**	**3**	**4**	**5**
5. I try to let off steam.	**1**	**2**	**3**	**4**	**5**
6. I talk to someone to find out more about the situation.	**1**	**2**	**3**	**4**	**5**
7. I focus my efforts on changing the situation.	**1**	**2**	**3**	**4**	**5**
8. I try to adjust my expectations to meet the situation.	**1**	**2**	**3**	**4**	**5**
9. I tell myself the problem wasn't so serious after all.	**1**	**2**	**3**	**4**	**5**
10. I try to avoid thinking about the problem.	**1**	**2**	**3**	**4**	**5**
11. I try to relieve my tension somehow.	**1**	**2**	**3**	**4**	**5**
12. I ask a relative or friend I respect for advice.	**1**	**2**	**3**	**4**	**5**
13. I work on changing the situation to get what I want.	**1**	**2**	**3**	**4**	**5**
14. I try to adjust my own standards.	**1**	**2**	**3**	**4**	**5**
15. I tell myself that the problem wasn't such a big deal after all.	**1**	**2**	**3**	**4**	**5**

16. I try to turn my attention away from the problem.	**1**	**2**	**3**	**4**	**5**
17. I try to get it off my chest.	**1**	**2**	**3**	**4**	**5**
18. I talk to someone about how I was feeling.	**1**	**2**	**3**	**4**	**5**

(CCS [abbrv.], Guppy, Edwards, Brough, Peters-Bean, Sale & Short, 2004)

This section asks about the DEGREE of CONTROL OR INFLUENCE you have over YOUR LIFE. Please circle the answer that you find is most appropriate to you.

please reply to all the items.

Circle your response choice for each item on the table:

Items	**Strongly Agree**	**Agree**	**Disagree**	**Strongly Disagree**
1. I have little control over the things that happen to me.	**1**	**2**	**3**	**4**
2. There is really no way I can solve some of the problems I have	**1**	**2**	**3**	**4**
3. There is little I can do to change many of the important things in my life.	**1**	**2**	**3**	**4**
4. I often feel helpless in dealing with the problems of life.	**1**	**2**	**3**	**4**
5. Sometimes I feel that I'm being pushed around in life.	**1**	**2**	**3**	**4**
6. What happens to me in the future mostly depends on me.	**1**	**2**	**3**	**4**
7. I can do just about anything I really set my mind to.	**1**	**2**	**3**	**4**

(MS, Pearlin & Schooler, 1978)

Read each item and circle the box opposite the reply which comes closest to how you have been feeling in the past week. Don't take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought out response. please reply to all the items.

	CIRCLE YOUR CHOICE, ONE PER LINE			
1. I feel tense or 'wound up'	**Most of the time**	**A lot of the time**	**Time to time, Occasionally**	**Not at all**
2. I still enjoy the things I used to enjoy	**Definitely as much**	**Not quite so much**	**Only a little**	**Hardly at all**
3. I get a sort of frightened feeling as if something awful is going to happen	**Very definitely and quite badly**	**Yes, but not too badly**	**A little, but it doesn't worry me**	**Not at all**
4. I can laugh and see the funny side of things	**As much as I always could**	**Not quite so much now**	**Definitely not so much now**	**Not at all**
5. Worrying thoughts go through my mind	**A great deal of the time**	**A lot of the time**	**From time to time, but not too often**	**Only occasionally**
6. I feel cheerful	**Not at all**	**Not often**	**Sometimes**	**Most of the time**
7. I can sit at ease and feel relaxed	**Definitely**	**Usually**	**Not often**	**Not at all**
8. I feel as if I am slowed down	**Nearly all**	**Very**	**Sometimes**	**Not at all**

	the time	**often**		
9. I get a sort of frightened feeling like 'butterflies' in the stomach	**Not at all**	**Occasionally**	**Quite often**	**Very often**
10. I have lost interest in my appearance	**Definitely**	**I don't take so much care as I should**	**I may not take quite as much care**	**I take just as much care as ever**
11. I feel restless as if I have to be on the move	**Very much indeed**	**Quite a lot**	**Not very much**	**Not at all**
12. I look forward with enjoyment to things	**As much as ever I did**	**Rather less than I used to**	**Definitely less than I used to**	**Hardly at all**
13. I get sudden feelings of panic	**Very often indeed**	**Quite often**	**Not very often**	**Not at all**
14. I can enjoy a good book, radio or TV programme	**Often**	**Sometimes**	**Not often**	**Very seldom**

(HADS, Zigmond & Snaith, 1983)

We would like to know if you have had any medical complaints and how your health has been in general, over the last few weeks. Please answer ALL the questions simply by circling the answer which you think most nearly applies to you. Remember that we want to know about present and recent complaints, not those you had in the past. Have you recently ...

1.	been able to concentrate on whatever you're doing?	Better than usual	Same as usual	Less than usual	Much less than usual
2.	lost much sleep over worry?	Not at all	No more than usual	Rather more than usual	Much more than usual
3.	felt that you were playing a useful part in things	More so than usual	Same as usual	Less useful than usual	Much less useful
4.	felt capable of making decisions about things?	More so than usual	Same as usual	Less so than usual	Much less than usual
5.	felt constantly under strain?	Not at all	No more than usual	Rather more than usual	Much more than usual
6.	felt you couldn't overcome your difficulties?	Not at all	No more than usual	Rather more than usual	Much more than usual
7.	been able to enjoy your normal activities?	More so than usual	Same as usual	Less so than usual	Much less than usual
8.	been able to face up to your problems?	More so than usual	Same as usual	Less so than usual	Much less than usual
9.	been feeling unhappy and depressed?	Not at all	No more than usual	Rather more than usual	Much more than usual
10.	been losing confidence in yourself?	Not at all	No more than usual	Rather more than usual	Much more than usual
11.	been thinking of yourself as a worthless person?	Not at all	No more than usual	Rather more than usual	Much more than usual
12.	been feeling reasonably happy all things considered?	More so than usual	About same as usual	Less so than usual	Much less than usual

(GHQ, Goldberg & Blackwell, 1970)

We want to know how your health has been in general over the last week. Please read the questions below and each of the four possible answers and circle the number that best indicates how you think your health has been in general over the last week.

Items	Rarely	Sometimes	Moderately	Most of Time
1. I was bothered by things that don't usually bother me.	1	2	3	4
2. I did not feel like eating; my appetite was poor.	1	2	3	4
3. I felt that I could not shake off the blues, even with help from family or friends.	1	2	3	4
4. I felt I was just as good as other people.	1	2	3	4
5. I had trouble keeping my mind on what I was doing.	1	2	3	4
6. I felt depressed.	1	2	3	4
7. I felt everything I did was an effort.	1	2	3	4
8. I felt hopeful about the future.	1	2	3	4
9. I thought my life had been a failure.	1	2	3	4
10. I felt fearful.	1	2	3	4
11. My sleep was restless.	1	2	3	4
12. I was happy.	1	2	3	4
13. I talked less than usual.	1	2	3	4
14. I felt lonely.	1	2	3	4
15. People were unfriendly.	1	2	3	4
16. I enjoyed life.	1	2	3	4
17. I had crying spells.	1	2	3	4
18. I felt sad.	1	2	3	4
19. I felt that people dislike me.	1	2	3	4
20. I could not get "going."	1	2	3	4

(CES-D, Radloff, 1977)

Please feel free to add further comments:

Thank you very much for your help in completing this questionnaire.

APPENDIX B: Pilot Study Results

Table 1 Main attachment descriptive variables for ECR

ECR (n = 11)	Cronbachs α	Mean	SD
Avoidant	.94	42.45	19.54
Anxious	.86	57.45	17.70

Table2: Main descriptive variables for IPIP

IPIP (n = 11)	Cronbachs α	IPIP Mean	SD	Min- Max (possible)	Min – Max (scored)
Extraversion	.81	34.18	7.29	10-50	18-44
Agreeableness	.66	44.27	4.08	10-50	37-50
Conscientious	.64	37.36	5.32	10-50	29-46
Neuroticism	.86	26.36	7.41	10-50	11-34
Openness	.79	35.36	6.90	10-50	23-44

Table 3: Main descriptive variables for Mini IPIP

Mini IPIP (n = 11)	Cronbachs α	Mean	SD	Min-Max (possible)	Min – Max (scored)
Extraversion	.62	13.45	3.91	4 - 20	5 – 18
Agreeableness	.52	17.91	1.58	4 – 20	16 -20
Conscientiousness	.59	14.00	3.19	4 – 20	6– 18
Neuroticism	.57	10.09	3.02	4 – 20	4 – 15
Openness	.70	14.09	3.94	4 - 20	8 -18

Table 4: Main descriptive variables for CCS

CCS (n = 11)	Cronbachs α	Mean	SD	Min- Max (possible)	Min – Max (scored)
Coping overall	.74	60.54	8.24	18-90	48-74
Change	.82	9.55	2.73	3-15	5-13
Accommodate	.96	9.09	3.45	3-15	3-15
Devalue	.74	9.45	2.77	3-15	6-14
Avoid	.86	9.00	2.65	3-15	6-14
Symptom Reduction	.33	10.82	1.99	3-15	7-14
Support Seek	.81	12.63	2.34	3-15	9-15

Table 5: Main descriptive variables for MSPSS

MSPSS (n = 11)	Cronbachs α	Mean	SD	Min-Max (possible)	Min – Max (scored)
Perceived social support overall	.93	67.82	14.93	12-84	41-84
Significant other	.90	21.18	6.71	4-28	10-28
Family	.93	22.45	6.53	4-28	10-28
Friends	.85	24.18	3.68	4-28	17-28

Table 6: Main descriptive variables for RSES

RSES (n = 11)	Cronbachs α	Mean	SD	Min- Max (possible)	Min – Max (scored)
Self esteem	.72	32.27	4.05	10-40	28-39

Table 7: Main descriptive variables for L of C

L of C (n = 11)	Cronbachs α	Mean	SD	Min-Max (possible)	Min – Max (scored)
Locus of control	.71	10.09	3.99	0-21	2-15

Table 8: Main descriptive variables for HADS, GHQ and CES-D

Psychopathological (n = 11)	Cronbachs α	Mean	SD	Min-Max (possible)	Min-Max (scored)
HADS o/all	.83	8.73	5.24	0-42	1-15
HADS anxiety	.85	6.18	4.02	0-24	0-12
HADS depression	.76	2.55	2.34	0-24	1-8
GHQ	.90	10.63	4.92	0-36	6-22
CES-D	.87	25.36	7.17	20-80	20-40

APPENDIX C: Questionnaire for the Main Study

PART 1 – BACKGROUND INFORMATION

Are you male or female? Male [ ] Female [ ]

What age are you? [ ]

Ethnic background? British [ ] Irish [ ] other European [ ]

American [ ] Afro/Caribbean [ ]

Asian [ ] New World [ ] other [ ]

Marital status? Single [ ] Married [ ] Separated [ ]

Divorced [ ] Co-habiting [ ] Widow/er [ ]

How long in current relationship? No current relationship [ ] Less than 3 months [ ]

3 - 6 months [ ] 6 months – 2 years [ ]

2 – 5 years [ ] 5 + years [ ]

How long in previous relationship? _____

How do you rate your current relationship? [ ]

Where, 1 means extremely unsatisfactory

2 means unsatisfactory

3 means satisfactory

4 means extremely satisfactory

Are you working at the moment? Yes/ No*

If so, what as? _____

What is your annual income? Under £10,000 [ ] £10,001 – 15,000 [ ]

£15,001 – 20,000 [ ] £20,001 – 30,000 [ ] £30,001 – 45,000 [ ]
£ 45,001 – 70,000 [ ] £70,001 + [ ]

What educational qualifications did you gain? None [ ] Technical [ ]GCSE [ ]

'A' levels [ ] Degree [ ] Postgrad [ ]

What was the highest educational qualification your mother gained? _____

What was the highest educational qualification your father gained? _____

Which religion are you? _____

Do you attend religious worship regularly? Yes / No*

Are your parents divorced? Yes / No*

If yes, what age were you when they divorced? _____

Did the absent parent maintain regular contact with you? Yes / No*

Do you have any current medically diagnosed illness? Yes / No*

If yes, what is it? _____

How many brothers and sisters (siblings) do you have? [ ]

In which order were you born? *ie.,1st, 2nd, 3rd, 4th,etc.* [ ]

Had you a sibling with a disability that required increased parental involvement? Yes/No*

* Please delete as appropriate

If you have answered 'yes' to this question please continue to answer the rest of the questions.

If not, please move on to the next section (Part 2).

What is the current age of your disabled sibling? (If deceased, please put age of death*)* [ ]

How is the severity of the disability classed? *Where, 1 means mild* [ ]

2 means moderate

3 means severe

4 means profound

What was the age of your sibling when the disability was first suspected? [ ]

Has your sibling been medically diagnosed? Yes [ ] No [ ]

If so, what has your sibling been diagnosed with? _____

What was the age of your sibling when the disability was first diagnosed? [ ]

Is there a prognosis? Yes [ ] No [ ]

If so, what is the prognosis (expected long-term outcome?

_____

In which order was your disabled sibling born? *ie., 1st, 2nd, 3rd, 4th, etc* [ ]

Is your disabled sibling living with you? Yes [ ] No [ ]

If so, are you the primary (main) carer for your disabled sibling Yes [ ] No [ ]

How well do you think your mother adjusted to having a disabled child? [ ]

Where, 1 means very well - disability incorporated into normal family life

2 means quite well – usually coped with disability but periods of difficulty coping

3 means average – family life usually functional, but constant ups and downs re disability

4 means quite poorly – generally overwhelmed by disability, but controlled

5 means very poorly – family life completely revolved around disability

6 means extremely poorly – acted as if disability was inconvenience and did not exist

How well do you think your father adjusted to having a disabled child? [ ]

Please use 1- 6 scoring scale, as above.

PART 2

For <u>each</u> of the three descriptions below please indicate how far you feel each describes your mother's behaviour towards you when you were a child, by putting a number between 1 and 7 in the box,

where, 1 means strongly disagree

2 means disagree

3 means slightly disagree

4 means neither agree nor disagree

5 means slightly agree

6 means agree

7 means strongly agree

She was generally warm and responsive; she was good at knowing when to be supportive and when to let me operate on my own; our relationship was almost always comfortable, and I have no major reservations or complaints about it.	
She was fairly cold and distant, or rejecting, not very responsive; I wasn't her highest priority, her concerns were often elsewhere; it's possible that she would just as soon not have had me.	
She was noticeably inconsistent in her reactions to me, sometimes warm and sometimes not; she had her own agendas which sometimes got in the way of her receptiveness and responsiveness to my needs; she definitely loved me but didn't always show it in the best way.	

For <u>each</u> of the three descriptions below please indicate how far you feel each describes your father's behaviour towards you when you were a child, by putting a number between 1 and 7 in the box

where, 1 means strongly disagree

2 means disagree

3 means slightly disagree

4 means neither agree nor disagree

5 means slightly agree

6 means agree

7 means strongly agree

He was generally warm and responsive; he was good at knowing when to be supportive and when to let me operate on my own; our relationship was almost always comfortable, and I have no major reservations or complaints about it.	
He was fairly cold and distant, or rejecting, not very responsive; I wasn't his highest priority, his concerns were often elsewhere; it's possible that he would just as soon not have had me.	
He was noticeably inconsistent in his reactions to me, sometimes warm and sometimes not; he had his own agendas which sometimes got in the way of his receptiveness and responsiveness to my needs; he definitely loved me but didn't always show it in the best way.	

(DPCS, Hazen & Shaver, 1986)

Please try to answer the following questions as honestly as possible. It will be useful if you can describe yourself as you feel you compare to others of the same sex and approximate age group. Please circle the number you think is most appropriate.

Items	**Very Inaccurate**		**Neutral**		**Very Accurate**
1. Am the life of the party.	1	2	3	4	5
2. Feel little concern for others.	1	2	3	4	5
3. Am always prepared.	1	2	3	4	5
4. Get stressed out easily	1	2	3	4	5
5. Have a rich vocabulary.	1	2	3	4	5
6. Don't talk a lot.	1	2	3	4	5
7. Am interested in people.	1	2	3	4	5
8. Leave my belongings around.	1	2	3	4	5
9. Am relaxed most of the time.	1	2	3	4	5
10. Have difficulty understanding abstract ideas.	1	2	3	4	5
11. Feel comfortable around people.	1	2	3	4	5
12. Insult people.	1	2	3	4	5
13. Pay attention to details.	1	2	3	4	5
14. Worry about things.	1	2	3	4	5
15. Have a vivid imagination.	1	2	3	4	5
16. Keep in the background.	1	2	3	4	5
17. Sympathise with others' feelings.	1	2	3	4	5
18. Make a mess of things.	1	2	3	4	5
19. Seldom feel blue.	1	2	3	4	5
20. Am not interested in abstract ideas.	1	2	3	4	5

21. Start conversations.	1	2	3	4	5
22. Am not interested in other people's problems.	1	2	3	4	5
23. Get chores done right away.	1	2	3	4	5
24. Am easily disturbed.	1	2	3	4	5
25. Have excellent ideas.	1	2	3	4	5
26. Have little to say.	1	2	3	4	5
27. Have a soft heart.	1	2	3	4	5
28. Often forget to put things back in their proper place.	1	2	3	4	5
29. Get upset easily.	1	2	3	4	5
30. Do not have a good imagination.	1	2	3	4	5
31. Talk to a lot of different people at parties.	1	2	3	4	5
32. Am not really interested in others.	1	2	3	4	5
33. Like order.	1	2	3	4	5
34. Change my mood a lot.	1	2	3	4	5
35. Am quick to understand things.	1	2	3	4	5
36. Don't like to draw attention to myself.	1	2	3	4	5
37. Take time out for others.	1	2	3	4	5
38. Shirk my duties.	1	2	3	4	5
39. Have frequent mood swings.	1	2	3	4	5
40. Use difficult words.	1	2	3	4	5
41. Don't mind being the centre of attention.	1	2	3	4	5
42. Feel others' emotions.	1	2	3	4	5

43. Follow a schedule.	1	2	3	4	5
44. Get irritated easily.	1	2	3	4	5
45. Spend time reflecting on things.	1	2	3	4	5
46. Am quiet around strangers.	1	2	3	4	5
47. Make people feel at ease.	1	2	3	4	5
48. Am exacting in my work.	1	2	3	4	5
49. Often feel blue.	1	2	3	4	5
50. am full of ideas.	1	2	3	4	5

(IPIP, Goldberg, 1999)

The following statements concern how you feel in romantic relationships. We are interested in how you generally experience relationships, not just in what is happening in a current relationship. Respond to each statement by circling how much you agree or disagree with it.

Items	**Disagree Strongly**			**Neutral**			**Agree Strongly**
1. I prefer not to show a partner how I feel deep down.	1	2	3	4	5	6	7
2. I worry about being abandoned.	1	2	3	4	5	6	7
3. I am very comfortable being close to romantic partners	1	2	3	4	5	6	7
4. I worry a lot about my relationships	1	2	3	4	5	6	7
5. Just when my partner starts to get close to me I find myself pulling away.	1	2	3	4	5	6	7
6. I worry that romantic partners won't care about me as much as I care about them	1	2	3	4	5	6	7
7. I get uncomfortable when a romantic partner wants to be very close.	1	2	3	4	5	6	7
8. I worry a fair amount about losing my partner.	1	2	3	4	5	6	7
9. I don't feel comfortable opening up to romantic partners.	1	2	3	4	5	6	7
10. I often wish that my partner's feelings for me were as strong as my feelings for him/her.	1	2	3	4	5	6	7
11. I want to get close to my partner, but I	1	2	3	4	5	6	7

keep pulling back.							
12. I often want to merge completely with romantic partners, and this sometimes scares them away.	1	2	3	4	5	6	7
13. I am nervous when partners get too close to me.	1	2	3	4	5	6	7
14. I worry about being alone	1	2	3	4	5	6	7
15. I feel comfortable sharing my private thoughts and feelings with my partner.	1	2	3	4	5	6	7
16. My desire to be very close sometimes scares people away.	1	2	3	4	5	6	7
17. I try to avoid getting too close to my partner.	1	2	3	4	5	6	7
18. I need a lot of reassurance that I am loved by my partner.	1	2	3	4	5	6	7
19. I find it relatively easy to get close to my partner.	1	2	3	4	5	6	7
20. Sometimes I feel that I force my partners to show more feeling, more commitment.	1	2	3	4	5	6	7
21. I find it difficult to allow myself to depend on romantic partners.	1	2	3	4	5	6	7
22. I do not often worry about being abandoned.	1	2	3	4	5	6	7
23. I prefer not to be too close to romantic partners.	1	2	3	4	5	6	7
24. If I can't get my partner to show interest	1	2	3	4	5	6	7

in me, I get upset or angry.							
25. I tell my partner just about everything.	1	2	3	4	5	6	7
26. I find that my partner(s) don't want to get as close as I would like.	1	2	3	4	5	6	7
27. I usually discuss my problems and concerns with my partner.	1	2	3	4	5	6	7
28. When I'm not involved in a relationship, I feel somewhat anxious and insecure	1	2	3	4	5	6	7
29. I feel comfortable depending on romantic partners.	1	2	3	4	5	6	7
30. I get frustrated when my partner is not around as much as I would like.	1	2	3	4	5	6	7
31. I don't mind asking romantic partners for comfort, advice, or help.	1	2	3	4	5	6	7
32. I get frustrated if romantic partners are not available when I need them.	1	2	3	4	5	6	7
33. It helps to turn to my romantic partner in times of need.	1	2	3	4	5	6	7
34. When romantic partners disapprove of me, I feel really bad about myself.	1	2	3	4	5	6	7
35. I turn to my partner for many things, including comfort and reassurance.	1	2	3	4	5	6	7
36. I resent it when my partner spends time away from me.	1	2	3	4	5	6	7

(ECR, Brennan, Clark & Shaver, 1998)

Below is a list of statements indicating how much you feel that you can rely on others for support. Please answer each question by circling the number you feel is most accurate.

Items	**Disagree Strongly**			**Neutral**			**Agree Strongly**
1. There is a special person who is around when I am in need.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
2. There is a special person with whom I can share my joys and sorrows.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
3. My family really tries to help me.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
4. I get the emotional support and help I need from my family.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
5. I have a special person who is a great source of comfort to me.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
6. My friends really try to help me.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
7. I can count on my friends when things go wrong.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
8. I can talk about my problems with my family.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
9. I have friends with whom I can share my joys and sorrows.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
10. There is a special person in my life who cares about my feelings.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
11. My family is willing to help me make decisions.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
12. I can talk about my problems with my friends.	**1**	**2**	**3**	**4**	**5**	**6**	**7**

(MSPSS, Zimet, Dahlem, Zimet & Falrley, 1988)

This section asks about the VIEWS people hold about THEMSELVES. please reply to all the items. Circle your response choice for each item on the table:

Items	**Disagree Strongly**	**Disagree**	**Agree**	**Agree Strongly**
1. On the whole I am satisfied with myself.	1	2	3	4
2. At times, I think I am no good at all.	1	2	3	4
3. I feel that I have a number of good qualities.	1	2	3	4
4. I am able to do things as well as most other people.	1	2	3	4
5. I feel I do not have much to be proud of.	1	2	3	4
6. I certainly feel useless at times.	1	2	3	4
7. I feel that I am a person of worth, at least on an equal plane with others.	1	2	3	4
8. I wish I could have more respect for myself.	1	2	3	4
9. All in all, I am inclined to feel that I am a failure.	1	2	3	4
10, I take a positive attitude towards myself.	1	2	3	4

(RSES, Rosenberg, 1965)

The questions below are concerned with how you GENERALLY cope with problems in YOUR LIFE. Please circle your response choice for each item in the table below.

Items	Never	rarely	some-times	often	always
1. I try to change the situation to get what I want.	1	2	3	4	5
2. I make an effort to change my expectations.	1	2	3	4	5
3. I tell myself the problem was unimportant.	1	2	3	4	5
4. I try to keep myself from thinking about the problem.	1	2	3	4	5
5. I try to let off steam.	1	2	3	4	5
6. I talk to someone to find out more about the situation.	1	2	3	4	5
7. I focus my efforts on changing the situation. 8. I try to adjust my expectations to meet the situation.	1 1	2 2	3 3	4 4	5 5
9. I tell myself the problem wasn't so serious after all.	1	2	3	4	5
10. I try to avoid thinking about the problem.	1	2	3	4	5
11. I try to relieve my tension somehow. 12. I ask a relative or friend I respect for advice. 13. I work on changing the situation to get what I want.	1 1 1	2 2 2	3 3 3	4 4 4	5 5 5
14. I try to adjust my own standards.	1	2	3	4	5
15. I tell myself that the problem wasn't such a big deal after all.	1	2	3	4	5
16. I try to turn my attention away from the problem.	1	2	3	4	5
17. I try to get it off my chest.	1	2	3	4	5
18. I talk to someone about how I was feeling.	1	2	3	4	5

(CCS [abbrv.], Guppy, Edwards, Brough, Peters-Bean, Sale & Short, 2004)

This section asks about the DEGREE of CONTROL OR INFLUENCE you have over YOUR LIFE. Please circle the answer that you find is most appropriate to you.

please reply to all the items.

Circle your response choice for each item on the table:

Items	**Strongly Agree**	**Agree**	**Disagree**	**Strongly Disagree**
1. I have little control over the things that happen to me.	1	2	3	4
2. There is really no way I can solve some of the problems I have	1	2	3	4
3. There is little I can do to change many of the important things in my life.	1	2	3	4
4. I often feel helpless in dealing with the problems of life.	1	2	3	4
5. Sometimes I feel that I'm being pushed around in life.	1	2	3	4
6. What happens to me in the future mostly depends on me.	1	2	3	4
7. I can do just about anything I really set my mind to.	1	2	3	4

(MS, Pearlin & Schooler, 1978)

Read each item and circle the box opposite the reply which comes closest to how you have been feeling in the past week. Don't take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought out response. please reply to all the items.

	CIRCLE YOUR CHOICE, ONE PER LINE			
1. I feel tense or 'wound up'	Most of the time	A lot of the time	Time to time, Occasionall y	Not at all
2. I still enjoy the things I used to enjoy	Definitely as much	Not quite so much	Only a little	Hardly at all
3. I get a sort of frightened feeling as if something awful is going to happen	Very definitely and quite badly	Yes, but not too badly	A little, but it doesn't worry me	Not at all
4. I can laugh and see the funny side of things	As much as I always could	Not quite so much now	Definitely not so much now	Not at all
5. Worrying thoughts go through my mind	A great deal of the time	A lot of the time	From time to time, but not too often	Only occasionally
6. I feel cheerful	Not at all	Not often	Sometimes	Most of the time
7. I can sit at ease and feel relaxed	Definitely	Usually	Not often	Not at all

8. I feel as if I am slowed down	Nearly all the time	Very often	Sometimes	Not at all
9. I get a sort of frightened feeling like 'butterflies' in the stomach	Not at all	Occasionally	Quite often	Very often
10. I have lost interest in my appearance	Definitely	I don't take so much care as I should	I may not take quite as much care	I take just as much care as ever
11. I feel restless as if I have to be on the move	Very much indeed	Quite a lot	Not very much	Not at all
12. I look forward with enjoyment to things	As much as ever I did	Rather less than I used to	Definitely less than I used to	Hardly at all
13. I get sudden feelings of panic	Very often indeed	Quite often	Not very often	Not at all
14. I can enjoy a good book, radio or TV programme	Often	Sometimes	Not often	Very seldom

(HADS, Zigmond & Snaith, 1983)

Please feel free to add any further comments:

Thank you for your help in this research.

APPENDIX D: Ethical Approval

Copy

University of Chester: Psychology Department

Application to Departmental Ethics Committee (rev. 2.05)

[A copy of this form is on the Psychology Department IBIS site. If using the electronic version to produce an application please print on blue paper.]

Name of applicant: Linda O'Neill

Working title of research: Interplay of factors influencing the long-term attachment style and personality traits of well-siblings of disabled individuals

Aims and objectives of research (e.g. purpose of study, specific hypotheses): To ascertain if there are significant differences between attachment and personality variables and depression and anxiety scores in well-siblings of disabled individuals and a matched control group. This will further involve examining self-esteem, perceived social support, coping styles and control. The overall hypothesis is that well-siblings of disabled individuals will be significantly more at risk of developing internalizing disorders than the control group.

Procedure (brief outline of design, measures, etc.): Descriptives will be calculated, ANOVA to establish differences between the means, correlational analysis to establish any associations between the variables and multiple regression to look for specific predictors. Structural Equation Modeling to ensure inter-related variables find the line of best fit, t see if they fit the same theoretical model. Self report measures to be used are general demographic information, an adapted measure of Descriptions of Parental Caregiving Style (Hazen & Shaver, 1986), International Personality Item Pool (Goldberg, 1999), Experiences in Close Relationships (Brennan, Clark & Shaver, 1998), Rosenberg Self-Esteem Scale (Rosenberg, 1965), The Multidimensional Scale of Perceived Social Support (Zimet, Dahlem, Zimet & Farley, 1988), Cybernetic Coping Scale (Guppy et al., 2004), Locus of Control Scale (Rotter, 1966). And one of the following measures – Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1989) or General Health Questionnaire (Goldberg & Blackwell, 1970) or Center of Epidemiological Studies – Depression Scale (Radloff, 1977).

Participants (e.g. sample size, age-group, how recruited): A minimum of 100 siblings of disabled individuals, recruited through charities such as Cheshire Carers Project, Mencap and Social Services. The age range will be 18+. The participants will be matched with a control group either recruited on campus or through local organizations.

Will informed consent be sought? (If so, how?) Yes, informed consent will be sought. This will be through a letter giving a brief synopsis of the study, which will be attached to the front of every questionnaire. It will inform the participant that the study will be anonymous, also that the participant has the right to withdraw at any time and further if they are sensitive to any particular question they heave the right to leave it blank.

Is deception involved? (If yes, explain and say if and how a debrief will be used.) No.

How will issues of confidentiality be dealt with? All the respondents will return the unnamed questionnaires in a pre-addressed envelope to the Psychology Department at the University of Chester. The envelopes will be chosen randomly when the data is to be input. The questionnaire will nit be numbered or marked in any way.

Are there issues of possible harm, discomfort or distress? (If yes, how will these be dealt with?) No harm or distress is anticipated, however, the participants will be informed of helpline numbers, such as The Samaritans, on the accompanying letter.

Is any other consent or ethics approval needed before carrying out this study? (If yes, give details.) No.

Please note that you should append additional information as necessary (e.g., information sheet for participants, copies of questionnaires or other measures to be used, experimental protocols, interview schedules, etc.). If you do not give sufficient information for the Committee to make a decision your application will be delayed pending further information.

I confirm that I have read: (1) the current version of *Ethical Principles in Psychological Research with Human Participants* produced by the British Psychological Society; (2) the *Code of Practice Concerning Ethical Principles for Research* produced by Chester College of HE. (Both documents are available in the Psychology Department.)

Signed: ____Linda O'Neill_____ (Applicant) Date: ___21st June, 2007_____

Supervisor to complete:

Have you discussed ethical issues with the applicant?

Please comment on how the applicant intends to deal with ethical issues arising:

The questionnaire needs tidying up but given informed consent there should be no major ethical issue

Signed: _____(Supervisor) Date: _____

****

Decision of committee:

☑ ACCEPTABLE*

☐ ACCEPTABLE SUBJECT TO CONDITIONS BELOW*

☐ REVISE AND RESUBMIT

[*Note to supervisor/applicant: Risk assessment needed before data collection: YES ☐ NO ☑]

Signed: _____ for (Chair) Date: 26/6/07

****

Chair's comments (if any):

APPENDIX E: Copy of Advertising Brief

ATTENTION!! REQUEST TO SIBLINGS OF THE LEARNING DISABLED!

The University of Chester is setting up a research project to establish if there are any long-term effects on well-siblings due to having a brother or sister with a learning disability. The research will examine the attachment styles and personality traits of the well-siblings - this will be to establish if there are underlying factors that can then be associated with levels of self esteem, perceptions of social support, differences in coping styles and perceptions of control. In order to establish if there are significant effects the siblings will be matched with a group drawn from the general population that will be as similar to them as possible, in terms of age, marital status, social economic status, etc.

There is very little information available regarding this important topic; consequently, this research will aim to look at the long-term effects of disability upon siblings - both good and bad, in order to establish if interventions may ultimately benefit this valuable section of society. Their emotional welfare is considered to be of great importance for many reasons including the well-sibling often bearing ultimate responsibility for their disabled brother or sister when the parent(s) become unable to.

The help requested is the completion of a questionnaire, which should take approximately thirty minutes. If you feel you can possibly help in this necessary research, and are over 18 years of age, please contact Linda O'Neill at the Psychology Department, University of Chester, Parkgate Road, Chester, CH1 4BJ, or at , or telephone no (weekdays). This will enable you to request a questionnaire and further information regarding the project.

Thank you for taking the time to read this and we look forward to hearing from you.

Yours,

Linda O'Neill

APPENDIX F: Letter of Request

Dear Sir/Madam

Research is being undertaken by the University of Chester to establish if there are any long term psychological effects on the brothers and sisters of disabled individuals. Research in this area has been extremely limited but it is deemed necessary to establish the psychological health of the well-sibling because of the growing population of individuals with disabilities. Currently there is little knowledge available if any familial or social adjustments need to be made in order to ensure the welfare of the well-sibling. In order to establish if there are significant findings it will be necessary to match the well-siblings with a control group drawn from the general population.

Your help is sought in order to fulfil this project. Briefly, the study will be looking at generally at development and personality types. Also examined will be perceptions of self-esteem, social support, control, coping styles and general well-being. If you would like to take part please complete the questionnaire and return it to the Psychology Department, University of Chester. Please see information sheet for details.

If you have questions about any aspect of the study please contact Linda O'Neill, either at or on the above address or telephone number. Any further questions can be directed to Dr. Lindsay Murray, Dr. David Scott or Professor Andrew Guppy, who are supervising this project, at the above address or telephone number. The data gathered from the study will be completely anonymous and will be used for academic purposes.

The questionnaire is not designed to cause distress but if you feel that it would be beneficial to discuss your feelings there are several national helplines designed to assist; these include the Samaritans at www.samaritans.org.uk , telephone number 08457 909090.

Thank you very much for your help in assisting this research.

Yours sincerely

Linda O'Neill,

Psychology Department, University of Chester

APPENDIX G: Information Sheet

INFORMATION SHEET

Background: A team from the University of Chester is carrying out a questionnaire study to look at the long-term effects of sibling learning disability upon well-siblings.

What does it involve? There are several short questionnaires about different aspects of personality, approach to different situations and emotional welfare. The questionnaires should take between 20 and 30 minutes to complete.

Consent: It is your choice if you would like to take part in the study. If you are unclear about any aspect of the study or if you have any further questions then please contact Linda O'Neill at or on . If you have any additional questions please contact Dr Lindsay Murray at the University of Chester address or on

Confidentiality: All details collected will be kept on a confidential database that is only accessible to those working on the project. The questionnaires are completed anonymously by the individuals with no identifying markers.

Reasons for the Study: There is very little information available regarding this important topic; consequently, this research will aim to look at the long-term effects of disability upon siblings - both good and bad, in order to establish if interventions may ultimately benefit this valuable section of society. Their emotional welfare is considered to be of great importance for many reasons including the well-sibling often bearing ultimate responsibility for their disabled brother or sister when the parent(s) become unable to.

Ethics: This project has been reviewed and passed by the University of Chester, Psychology Department Research Ethics Committee, which conforms to the ethical principles laid down by the British Psychological Society.

Ethical Issues: These questions are not designed to cause distress; however, if they do raise emotional issues for you that you would like to further discuss, there are a number of helplines available to you. These include www.samaritans.org.uk , telephone number 08457 909090.

Results: It is planned that preliminary aggregated results for the study will be available before spring, 2010 and that the full set of results will be available in summer, 2011. Please contact – for more information.

Thank you for your help in this project.